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ABSTRACT

This packet, a product of the Advancing Educational Techniques (AET) Project, addresses the theme of empowerment on the part of those working with children who are differently able. The first section explores the concept of empowerment as addressed in current literature and includes an annotated bibliography. Other sections of the packet focus on: (1) concepts used in viewing the family as a system; (2) issues confronting siblings of differently able children (with a resource list for siblings); (3) development of social skills in disabled children (again with bibliography); (4) family support; (5) Public Law 94-142 (the Education for All Handicapped Children Act), focusing on parental rights and responsibilities, the parent/school relationship, legal aspects and their implications for the provision of related services, and appeals cases; (6) the Individualized Education Plan (with sample form); (7) electronic networking with computers, centering on the SCHOLE system developed at Boston University; and (8) advocacy organizations and agencies, advocacy and recreational services in Massachusetts, and employment/vocational rehabilitation agencies. The last section contains several worksheets and instructions for their use, including the Primary Contact list, the Telephone Log, a Positive Contacts form, the Problem Solving Worksheet, and an activity description with form called "Our Family's Action Plan." There is also a brief article on the effective use of films for family discussion. The appendices include the Statewide Needs Assessment Instrument employed in an initial survey conducted under the auspices of the AET project, and a journal article reprint titled, "The Parent-Child Activity Group: Using Activities to Work with Children and Their Families in Residential Treatment" by Gino DeSalvatore and Deborah Rosenman. (PB)

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The PARENT *EMPOWERMENT* PACKET

P E P

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EC 220784

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Gerald S. Fain, Ph.D

Project Director

There is never enough time or resource to do all that is important in life. Each individual decides how to spend the time they have available, and sets priorities that shape their lives and the lives of those around them. In this way, we are what we do. Our actions are statements of values.

The work completed on this grant extends over a four year period. In 1983 I shared the excitement of the idea for this project with a small group of colleagues at Boston University. The challenge was to create a plan that was consistent with our priorities and the funding available from the United States Department of Education. After consultation with colleagues, Janet Sable and I wrote the proposal.

After completing the application, I remember a moment of reflection on what we had done. Janet and I realized that the scope of the work was ambitious and would require enormous effort if the expectations were to be met. Soon after submission of the proposal, Janet accepted a position on the faculty at Lyndon State College in Vermont. When we were notified that the project was approved for funding, I began to search for an individual to replace Janet. Fortunately Patricia Shank was attracted to the work and assumed the position of Project Coordinator. The work was begun without delay and has continued with the essential intensity over the past three years.

I take pride in the accomplishments of the project staff and others who gave time and talent to this work. The products created represent values and commitments consistent with our mission and serve as a basis for the continued research and service. I trust the reader will agree that the time resources devoted to this project were well spent.

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PARENT *EMPOWERMENT* PACKET

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PARENT EMPOWERMENT PACKET

PREFACE

The Parent Empowerment Packet (PEP) was designed for the purpose of providing written resources that address the theme of empowerment. It may be particularly helpful to parents and professionals who work with parents and their children who are differently able.

Because PEP is exceptionally large, it might be somewhat overwhelming at first glance. Our suggestion, therefore, is to digest the contents a bit at a time. For example, one section may be pulled out and used within a parent support group that wishes to discuss a certain theme or issue during one or several meetings. Or a professional may want to photocopy a list of organizations that might ease the transition of an individual back into the community. Some of the worksheets we have provided might be used by each of the family members for the purpose of getting every person's input on solving a particular problem. In short, we encourage you to use part or all of the materials in a way that is most helpful to your particular situation and most responsive to your particular needs.

P[illegible]ONS

The first section of PEP explores the concept of empowerment as it has been addressed in current literature. This literature review follows the empowerment model illustrated on the next page. An annotated bibliography follows the empowerment paper and provides a number of excellent resources for both parents and professionals.

KNOWLEDGE +	SKILLS +	ATTITUDES +	SUPPORT =	BEHAVIOR
Specific Disability	Parenting	Honesty	Respite	EMPOWERMENT
Developmental Stages	Networking	Respect	Networking	
Rights/Laws	Advocacy	Reinforcement	Counseling	
Resources Available	Intervention Strategies	Acknowledgement	Support Groups	

Figure 1: An Empowerment Model

KNOWLEDGE + SKILLS + ATTITUDES + SUPPORT = EMPOWERING BEHAVIORS

Shank, P. A. (1986). Advancing Educational Techniques Project, Boston, MA: Boston University Leisure Studies Program.

Self-empowerment implies that one has developed and nurtured the knowledge, skills, attitudes and support necessary to cope with and manage the specific challenges one is confronted with. Self-empowerment is a continuous process. Processing the behaviors leads to further self-empowerment.

Note: The content areas listed in Figure 1 are examples used for illustration purposes only and are not to be regarded as all-inclusive.

The second section of PEP explains some of the concepts used in systems thinking particularly as these relate to the family.

Sisters and Brothers is the title of the third section of PEP. The reader will fin[illegible]r that addresses some of the issues confronted by the siblings of some individuals who are differently able. A list of a variety of resources particularly appropriate for sisters and brothers is also included.

Social Skills is the topic of the next section and it is presented in the form of an open letter from parent to parent. An extensive bibliography is also provided here as well as some suggestions for creating a support network.

Jo Bower, Associate Planner for the Developmental Disabilities Council, has contributed a comprehensive paper on Family Support and this constitutes the fifth section in PEP.

Public Law 94-142 (P. L. 94-142) or the Education for All Handicapped Children Act of 1975 serves as the unifying theme for the next set of papers that address parents rights and responsibilities under the Law; recreation as a related service within P.L. 94-142; partnership between parent and school; legal aspects and their implications for the provision of related services, and descriptions of several appeals cases that have been brought before the Bureau of Special Education Appeals Board.

The seventh section of PEP poses some common questions and provides answers that pertain to the Individualized Education Plan (IEP). A sample IEP form is provided and each part is explained.

Telecommunications or electronic networking with computers is the topic discussed in the next section of PEP. Information about SCHOLE, the telecommunications network developed at Boston University, is described here.

A variety of Organizations and Agencies are listed in the ninth section of PEP. Addresses, phone numbers and a brief description is given for each. Ty[illegible] organizations listed include: national and local advocacy, disabilit[illegible], employment or vocational rehabilitation, professional (discipline-specific and general), recreation agencies in Massachusetts that provide services for people with disabilities, national sports associations dedicated to promoting sports opportunities for all people, and organizations concerned with travel for individuals who are differently able.

The last section of PEP provides several worksheets that were designed to assist in the empowerment process. Each form is accompanied by an explanation and suggestions for use.

In the appendices, the reader is provided with a copy of the survey instrument that was used in the conduct of the Statewide Needs Assessment which helped provide direction and guidance for the development of PEP. In Appendix B we have included an article that describes a parent-child activity group that combines the concepts of group and family systems theory with therapeutically planned activities as a tool for the assessment and treatment of children who have behavior disorders and their families.

We would be most interested in your feedback about any of the materials included in PEP and particularly which you found helpful and how you used them (i.e., parent/professional partnership group, parent support group, family discussions, etc.). Please send your comments and suggestions to:

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PARENT EMPOWERMENT PACKET

FOREWORD

In 1984, the U. S. Department of Education's Office of Special Education and Rehabilitative Services invited proposals that addressed the need for better education techniques to facilitate the transition of children with disabilities to community living. Boston University's Leisure Studies Program met the challenge and designed a project that had as its primary goal the development, implementation, evaluation and dissemination of responsive education techniques pertinent to the lives of these children and their families. The Department of Education accepted the proposal and provided Boston University with the necessary support to conduct the project.

The implementation plan for the Project (entitled, "Advancing Educational Techniques through a Statewide Recreation Network") was designed to occur over a three year period (1984 - 1987). The first year involved the identification of family needs as these related to the three major target areas. These were: (1) family cohesion, (2) social skills development, and (3) the effective utilization of therapeutic recreation as a related service under P.L. 94-142 (the Education for all Handicapped Children Act of 1975). The second and third years were devoted to designing, testing and disseminating grant products.

Background

The Project objectives were designed to be accomplished through the Statewide Recreation Network (SRN). This Network was developed in 1981 with partial support from the Massachusetts Council on Developmental Disabilities and represented persons in special education, therapeutic recreation, community recreation, vocational education, continuing education, advocacy groups, parents and consumers. The primary focus during this initial phase in the development of the SRN was to improve recreation service delivery on a statewide basis through coordination of services and to provide training for a variety of service delivery personnel in the use of previously identified social skill development curricula and techniques. Recreation programs were the vehicle through which these techniques were implemented.

Massachusetts was divided into six regions and after identifying the recreation service agencies in each of the regions, one agency was selected as the "lead organization." Through the coordinated efforts of the Boston University staff and the lead organizations, a consortium of representatives from the above listed service providers was established and through these multidisciplinary groups, the goals of the project were accomplished.

The approach of the SRN rested on concepts which optimize involvement and networking on the local level and on the precept that through effective communication, resource sharing and joint problem-solving across interest groups, children with disabilities receive more comprehensive service delivery. The SRN structure proved to be responsive to the statewide need for coordinating efforts at improving recreation service delivery to people with disabilities. Subsequ[illegible] in 1984, the U.S. Department of Education, Division of Special Projects [illegible] to support continuation of the SRN by sponsoring a new project [illegible]ld provide previously unavailable integrated recreation services to individuals in the local communities whose recreational needs were not being met or who had only segregated (that is, outside of "mainstream" community services) recreation opportunities available to them.

Through consistent contact with local consortia members, it became clear that despite good intentions, there were persistent needs that weren´t being met. For example, due to geographical constraints, the networking component of the SRN wasn't always effective: People had a difficult time getting together for planning meetings and necessary "brainstorming" and resource sharing sessions. There was a need for the development of better, more effective networking techniques.

An additional unmet need that became evident over the course of the first four years of the SRN concerned the lack of involvement of parents and families of individuals with disabilities in various types of service delivery systems (e.g., educational and recreational systems). It appeared that the establishment of parent-professional partnerships in one community (Association for the Support of Human Services, Westfield, Ma) just wasn't happening in other communities. It seemed that parents were often left to struggle on their own to get needed information and that professionals were left to struggle with the real communication challenges found within their own bureaucratic systems. For example, within the educational system parents (by law) are to be regarded as equal partners in the education of their children. Despite the fact that Public Law 94-142 had been in existence for nearly ten years, many parents remained unaware of the full intent and meaning of that law and their rights and responsibilities under it. Many professionals meanwhile were confronted with th[illegible] of not only meeting the requirements of the law pertaining to chi[illegible]ation but often doing so without guidance as to how to get parents [illegible]ctively involved.

Through our varied experiences with parents and professionals, we knew intuitively that the lack of partnership for the most part was non-intentional and due moreso to the lack of information about how to actually improve the situation. Our target audiences for the products we were to create under the

"Advancing Educational Techniques Project" (AET), therefore, were both parents and professionals.

GRANT ACTIVITIES AND PRODUCTS

DOCTORAL STUDENTS

One of the "products" of the AET Project was the provision of financial support for doctoral-level students to pursue studies that would enhance their ability to work more closely with families of individuals with disabling conditions. Individuals were selected from special education, therapeutic recreation, social work, developmental studies and counseling programs. Over the course of three years, five individuals were able to attend Boston University on a full-time semester basis, while three individuals received assistance to attend on a part-time basis. Aside from pursuing their programs of study, these research assistants were also responsible for assisting with the implementation of the Project's activities.

STATEWIDE NEEDS ASSESSMENT

The first activity undertaken by the Project staff was to review the existing [illegible] pertaining to our three target areas (family cohesion, social [illegible] development and P. L. 94-142). The purpose of this review was to identify and establish possible variables for inclusion in a statewide needs assessment and for providing a systematic base for preliminary interviews with individuals who were either parents or professionals or both (parent-professionals).

Thirty-five individuals were interviewed. Their input and the results of the literature review enabled the staff to construct a preliminary assessment instrument which was then submitted to the Project's fourteen-member Advisory Board for review and comment. Seven Board members responded to our request.

The final version of the needs assessment instrument (see Appendix A) contained 69 items arranged into seven sections. The variables included were either rated along a 3- or 4-point scale that permitted an assessment of the importance and the availability of certain processes or services or which sought agreement or disagreement with certain statements. Space for open-ended comment was also provided on the questionnaire.

The items on the questionnaire were grouped into four categories: IEP (Individual Education Plan), Therapeutic Recreation, Social Skills, and Family Cohesion. A number of items were classified into two categories. Each major factor was presented in at least two different items in a slightly modified way in order to enhance the instrument's reliability.

Approximately four hundred people representing various roles in the lives of children with disabilities were sent a needs assessment questionnaire. Individuals were identified through their participation in the SRN or were recommended for contact by SRN members or by those interviewed earlier. In order to involve as many parents as possible, a thorough search of parent support [illegible] was conducted. A number of groups were identified and contacted for the purpose of ascertaining their willingness to participate.

The final sample of 127 persons included parents, public and private school administrators, special and general educators, therapeutic and community recreators, occupational and physical therapists, social workers, and others involved in human services throughout Massachusetts. Results of the assessment are available from Boston University's Leisure Studies Program.

THE LEISURE EXCHANGE GAME™

The LEISURE EXCHANGE GAME was created for the purposes of enhancing family cohesion and communication, and for educating about leisure which we believe involves freedom, choice and responsibility, not just free-time or certain kinds of activities.

The game consists of a playing board, playing pieces, and a variety of activity and surprise cards that players respond to. Leisure experience cards are collected and bartered by players. Leisure knowledge, values, attitudes and memories are expressed and shared in a way that is fun and enlightening.

Content for the cards was compiled as a result of the author's experience in working with children and adults as well as from literature pertaining to leisure education. The game was field tested by individuals (children and adults) in families, institutions, college classrooms and in community recreation programs. These people provided feedback and suggestions that were very helpful in constructing the final version.

The LEISURE EXCHANGE GAME is appropriate for people of all ages and abilities and is available from Boston University's Leisure Studies Program.

THE SCHOLE [illegible]COMMUNICATIONS NETWORK

Schole (pronounced, sko-lay) was developed in response to the need for an improved means of networking, information gathering and sharing among people. Schole utilizes advanced computer technology and is quite simple to use.

This computer networking system was demonstrated during Special Education

Week, held in March, 1985 at Boston University. Since that time, membership has greatly increased and now includes users (called, research associates) in both the United States and Great Britain. Schole members include professionals in a variety of fields and disciplines as well as laypersons interested in education and access to information.

For more information about Schole and Schole membership, see the section on TelecommunicationS in the PEP Manual.

THE LEISURE EDUCATION VIDEOTAPE

The leisure education videotape was designed for the purpose of educating people about leisure. It focuses on variables such as freedom, choice, responsibility, and competency and uses a multimedia approach to get its message across.

The target audiences for the LEISURE EDUCATION VIDEOTAPE are parent groups, therapeutic recreators, educators and others interested in learning more about this vital, life-enhancing concept/experience. It is available from Boston University's Leisure Studies Program.

AET GRA[illegible]AR SERIES

Four AET Research Assistants prepared and presented educational seminars on the following topics:

- Family Systems
- Therapeutic Recreation Facilitation Techniques for Working with Families

- Empowerment
- Parent Support Groups

The target audience for these seminars was masters-level students majoring in special education and therapeutic recreation. The overall purpose was to provide these students with the opportunity to acquire knowledge, skills and positive attitudes that could enable them to work more closely with parents and families of individuals who are differently able.

A culminating activity in the Seminar Series was a Parent-Professional Weekend held in Western Massachusetts and affiliated with the Association for the Support of Human Services. This weekend provided both parents and professionals with the opportunity to develop the knowledge, skills and attitudes that could enhance partnership in the delivery of services.

THE PARENT EMPOWERMENT PACKET (PEP)

The final product of the AET is this PARENT EMPOWERMENT PACKET (PEP). Its background and purpose may be found in the next section entitled, Introduction.

THE PARENT EMPOWERMENT PACKET

INTRODUCTION

The PARENT EMPOWERMENT PACKET (PEP) is one result of many months of reading, talking, thinking and doing. It was developed as a result of parents and professionals working together, enjoined in a conspiracy of the sort described by Marilyn Ferguson (1980) in *The Aquarian Conspiracy*: We have breathed together in a space that reflects and respects our interconnectedness.

BACKGROUND OF THE PEP

The Project staff chose to begin its journey where others left off. Both manual and computer searches were conducted for the purpose of determining what already existed in the literature that pertained to our target areas. Oftentimes, what we found was discouraging and disheartening, particularly in the so-called "professional literature." Approaching the readings from the perspective of a parent led one to believe in the inevitability of dysfunctional systems in relation to individuals with disabling characteristics. For example, it seemed that [illegible] we picked up an article written by a professional pertaining to famil[illegible] happened to have a member with a disability, that family was labeled, "the handicapped family," and therefore, *by virtue of that label*, regarded as an entity requiring intervention by this professional or that.

Occasionally, we did come across books and articles that were honest, thought-provoking, inspiring and helpful without being condescending and handicappist in tone. Most often, these were written by parents for parents or by professionals who were either parents themselves or who had a humanistic viewpoint of people that begins with and therefore emphasizes the importance of an individual's total being as opposed to the questionable centrality of his or her "handicaps."

The direction we were to take was largely influenced by both types of literature. We were determined to move away from the former and closer to the latter in our own efforts to provide resources that had the potential for being meaningful to parents as well as professionals interested and involved in contributing to the growth process of those individuals with challenges that require specific interventions.

The PARENT EMPOWERMENT PACKET is one product of that effort.

PACKET RESOURCES

The resources we have chosen to include in PEP had to "fit" within a certain paradigm of assumptions and had to meet two very important criteria. Those premises from which we worked will be presented first, and then the specific criteria we used for selecting materials will be outlined.

ASSUMPT[illegible]

During the course of the PEP development, certain premises or assumptions were made about families, professionals, handicaps and the concept of empowerment. These, then, served to guide the Project staff in establishing resource selection criteria.

I. Families with one or more members with disabling conditions

- are confronted with challenges typical to all families,
- are confronted with challenges that are specific to their particular system with its own norms, values, beliefs, structures and roles,
- are best viewed from a systems approach as is any set of interrelated, interdependent parts forming some coherent whole,
- viewed as living systems, are able to continuously renew, develop and become self-empowered.

II. Professionals

- in order to be effective participants in processes of empowerment, must view the individual from a perspective of holism,
- are not omnipotent and omniscient; they are human beings who have the ability to help as much as they have the ability to hurt,
- must work with individuals and their families, not become directors of them,
- can learn as much or more from the individuals for whom they provide services as they can from each other.

III. Empowerment

- as an idea is growth-enhancing and dynamic,
- as a process is developmental and ongoing,
- as a practice is most meaningful when intrinsically motivated and consistently nurtured,
- as a result is most long-lasting when it is developed from an internal rather than an external locus of control.

IV. Handicaps

- can be externally imposed such as those manifested in society in the form of attitudinal, architectural, educational and institutional barriers,

- can be self-imposed such as those that result from attempting to function from a perspective of learned helplessness and dependency,
- along with words such as "handicapped" and "handicappist," are best left to sports wherein their meaning is couched in equity and integration rather than inequity and segregation.

CRITERIA FOR SELECTION OF PEP MATERIALS

The resources included in this packet had to meet two important criteria. First, they had to have potential for enhancing the process of self-empowerment, and second, they had to address parents and children -- regardless of personal characteristics -- from a humanistic perspective which recognizes and celebrates individuality and uniqueness and the sanctity of personhood while acknowledging the interrelatedness of all people.

The theme of empowerment was purposefully selected. Unlike a normative definition that presents the concept of power from an external locus (i.e., to auth[illegible]legate power to something or someone), we preferred a dynamic interp[illegible] that suggests an internal locus of power and control. We believe that having, using and creating knowledge and developing and nurturing positive attitudes and growth-enhancing skills will eventuate into enabling behaviors that become an integral part of the self. Self-empowerment represents a movement towards a realization of one's own potential and strength. Furthermore, what empowers an individual will affect the empowerment of the system, whether that system is the family, an agency, a body of professionals or a societal institution.

The humanistic perspective insists that human beings are motivated toward unity and wholeness and are always in the process of becoming. As such, human personalities are infinitely expandable when the emphasis in functioning is on possibilities and potentials. There are no givens that imply that a particular system (an individual or a family) is handicapped because of certain characteristics which may be present or lacking. The humanistic view also emphasizes relationships, rather than isolated parts, and the inherent dynamics within relationships. This is particularly relevant when addressing either family systems or professional systems.

RESOURCES IN THE PEP

The binder we selected to encase our materials is deliberately large. In keeping with our view that people are dynamic, and therefore, so are their needs and interests, we chose a three-ring binder so that resources could continually be updated, added-to or changed as the user sees fit. Our intent in providing resources was to contribute to the process of self-empowerment by sharing what we have found or developed thus far.

[illegible] some of the materials will be meaningful contributions to the reader[illegible]ction of empowering resources. Others may not be, as meaningful[illegible] subjective. Our selections were based on results of a statewide needs assessment conducted in 1985 among parents and a variety of human service professionals in the Commonwealth of Massachusetts and on an exhaustive review of the literature. To reiterate, our best source of identifying needs came from the parents who took the time to write down their own experiences and suggestions in books and articles or who took the time to talk with us and respond to our survey.

The PEP should be viewed as a tool rather than as a definitive reference on any particular topic. It is meant to be a beginning, not an end in itself. We have included a section that offers some suggestions for continuing the process of education and resource sharing. We have also included a form that was designed to elicit feedback from the PEP user as we believe that feedback is perhaps the most critical component in a systems approach to any product development or service delivery.

TARGETS: FAMILY COHESION, SOCIAL SKILLS AND LEISURE EDUCATION

Family cohesion, social skills, and leisure education are manifold constructs. Each has varied forms and instances within different frames of reference and in different times and space. Each is given meaning through the context in which its components are used. The Project staff addressed each construct as separate entities and as concepts that are interrelated: Each derives meaning from the other when viewed from a developmental and holistic perspective. For example, the family provides the first context of leisure learning [illegible] expression, and primary socialization learning and expression (Neal, [illegible]lly, 1982; Orthner, 1974). Family cohesion, defined as the emotional [illegible] that family members have toward one another, can be seen as one dimension of family behavior. In addition to emotional bonding concepts of separateness or connectedness, it consists of such concepts as boundaries, coalitions, time space, friends, decision-making, interests and recreation (Olson, Portner and Bell, 1982). Family cohesion can be seen along a continuum of low to high degrees.

Cohesion, socialization and leisure education cannot be regarded as separate entities without incorporating the assumption that they are intricately related to each other and therefore, affect each other. The reader will find that this interrelatedness is evidenced throughout the PEP materials.

PEP'S AUDIENCE

The PEP was a collaborative effort among parents, professionals and parent-professionals. We have attempted to gear those efforts toward the same group as potential readers, but particularly toward parents of children with disabilities that challenge the family unit's adaptability and cohesive functioning. Mostly, PEP is directed toward anyone who simply seeks for ways that have some potential for encouraging the bond of humanness that we all share.

We welcome your impressions, criticisms and contributions to this ever-evolving product. Together, in partnership, we can make a difference in the lives of each other, and most importantly, in the lives of our children.

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EMPOWERMENT

Through a review of current literature, the notion of empowerment is explored in this section of the PEP. The paper is followed by a bibliography which lists several resources that have the potential of enhancing family empowerment.

PARENT EMPOWERMENT: A REVIEW OF THE LITERATURE

by Susan M. Hansen and Patricia A. Shank

Empowerment, as defined by Webster (1966), "is the act of giving authority or power;" it means to authorize something or someone, to give ability to or to enable something or someone. In an attempt to identify literature that addresses the concept of empowerment as it applies to parents of children with disabilities, one is struck with the knowledge that not much exists.

To be sure, since the passage of Public Law 94-142 (Education for All Handicapped Children Act of 1975), there has been an increasing awareness of issues surrounding what has come to be termed, "the exceptional family." Many parents believe, however, that although there is a glut of professional literature, much of it does not necessarily correlate with their own experiences of themselves as individuals, as parents or as the active partners they know they can be in the education of their children. Finding literature that demonstrates a natural respect for family resources, that refuses to focus on so-called deficits or to be lured by labels, and that shows evidence of a keen knowledge of systemic phenomena (Coppersmith, 1984) is a monumental task. Furthermore, many parents believe that what they read does not necessarily correlate with what they know, i.e., what they have observed and experienced in regard to the amount and kind of services and supports that are available in their own communities (Buscaglia, 1983; Dickman, 1985).

In this review of the literature, we have attempted to provide a more in-depth look at the concept of empowerment, discuss its relevance to families that have a member with unique challenges, and share with the reader pertinent materials and research that pertain to the components of the concept of empowerment as we will present it.

When asked to reflect on advice about counseling parents, one mother of a child with a disability wrote:

> All human beings can learn from one another and have a capacity and desire to share experiences with each other. No individual has all the answers, and this includes many "experts." Parents want the best for their children, have concerns that they consider unique to them (which may or may not be unique), have concerns for the health and safety of their children, want their children to become successful adults, want to improve as parents, have difficulty in opening up to professionals, find it easier to communicate with other parents, know more about their child than anyone else, and have the ultimate responsibility for their children.
>
> Parents of handicapped children have a sense of failure as a result of producing a handicapped child. They need support and reassurance in their roles as parents; need to know that it is OK to have both good and bad feelings about their handicapped kids; need to understand that they, as well as the child, are growing and changing; have the need to nurture their child while recognizing its striving for independence and separation in its growth to adulthood; and yet need to accept and understand the limitations the handicap may place on these goals. Most of all, the special knowledge and expertise of the parent should be recognized by the professional (Murphy, 1981, p. 94).

The needs and concerns so well articulated by this mother exemplifies those that will be addressed in this paper. One of the key issues we have found is the need for taking some of the pressure off parents so that they may perhaps feel more able to adopt what one professional has termed the "five R´s of family life": Regularity, Routine, Repetition, Relaxation and Reinforcement (Thrash, 1978).

The need for tangible resources that contribute to a parent´s quest for self-empowerment is paramount. Much of the professional literature available demonstrates a disturbing bias toward an emphasis on family dysfunction, often highlighted by the language used such as "the handicapped family" (Roberts, in Coppersmith, 1984, p. 3). Counseling techniques, experimental programs and a plethora of data are plentiful; however, the reader can't help but react to the assumptions of the presence of neuroses and chronic sorrow in the families being discussed -- as if these states of being are somehow inevitable when one becomes a parent of a child with handicapping conditions. The actual experiences shared by many parents who have been able to relieve some of the pressures associated with parenting indicate that there are no inevitables and no givens other than this: Armed with appropriate and necessary knowledge, skills, attitudes and support, parents are able to take charge and become self-empowering individuals in spite of the multitude of barriers they confront during the process of their own and their children's growth and development.

It is important to point out, however, that empowerment is a dynamic concept. One parent, expressed the process in this way:

> As we parent over many years, our actual experience is such that we plateau and are very much in control for many years. Then we are sent back to the helpless feeling many of us dealth with at the onset of the birth or diagnosis as we approach an unexpected operation or other stressful event. We soon rally and take charge again, but the reality of the highs and lows of parenting a child with a developmental disability are ever present.

Figure 1 on the following page demonstrates some examples of the combination of personal resources which contribute to or effect enabling, empowering behaviors. They also illustrate the types of issues addressed in the literature that lend support to the theme of parent empowerment.

In A Difference in the Family, Helen Featherstone (1980) sights four ways in which a professional can help a family and each lends support to the

KNOWLEDGE	+	SKILLS	+	ATTITUDES	+	SUPPORT	=	BEHAVIOR
Specific Disability		Parenting		Honesty		Respite		EMPOWERMENT
Developmental Stages		Networking		Respect		Networking		
Rights/Laws		Advocacy		Reinforcement		Counseling		
Resources Available		Intervention Strategies		Acknowledgement		Support Groups		

Figure 1: An empowerment model*

KNOWLEDGE + SKILLS + ATTITUDES + SUPPORT = EMPOWERING BEHAVIORS

*Shank, P. A. (1986). Advancing Educational Techniques Project, Boston, MA: Boston University Leisure Studies Program.

Self-empowerment implies that one has developed and nurtured the knowledge, skills, attitudes and support necessary to cope with and manage the specific challenges one is confronted with. Self-empowerment is a continuous process. Processing the behaviors leads to further self-empowerment.

Note: The content areas listed in Figure 1 are examples used for illustration purposes only and are not to be regarded as all-inclusive.

variables of empowerment identified in Figure 1. She states:

> They [professionals] can identify and explain the child's problem [knowledge]. They can show respect [attitude] for the child him- or herslf, the parent and the relationship between them. They can offer concrete assistance -- services such as therapy [support], education [skills, knowledge] or corrective surgery. And they can support parents emotionally [support] (Featherstone, 1980, p. 78; bracketed terms added].

The purpose of any of these empowering strategies would be to introduce what Bateson (1979) labeled, "News of a Difference." Each family will fight its own idiosyncratic battles and will look for its own idiosyncratic solutions. When approached from this stance, the literature is indeed full of "news" that can be interpreted and applied to the empowerment model we have outlined in Figure 1.

In order to understand the impact of much of the literature, one must first acknowledge that the introduction of a disability within a family system can cause a "structural problem" for that family. Minuchin (1974) addressed the need for families to have what he called "boundaries" within the family system (see also PEP section on "systems"). These boundaries must be flexible yet firm. For example, the married couple frees themselves from their families of origin in their attempt to be seen as a separate unit. The marital dyad sets up its own boundaries that allow each person to share and be seen as separate entities. The introduction of children into the system changes the structure further, and thus creates two basic systems, one of parents, one of siblings. The two basic subsystems then begin to share and complement each other. Though Minuchin does not specifically address the "exceptional family" in his models, the effects of disability on the organizational structure of the family holds true.

The presence of a disability typically strains the family boundaries at two points. The first is within the family itself while the second is around the perimeters of the family (Featherstone, 1980, p. 109). Very often, a child with a disabling condition has difficulty comfortably "fitting into" a sibling subsystem or within the larger system of society. Because of the extra time and care often demanded by the disability, parents find that their own time together as well as the time they have to spend with the other children is severely taxed. The organization of the family unit can suffer greatly when the emphasis (power) is placed within the needs of any one member.

Parent empowerment is aimed at re-introducing balance, that is, restructuring the family organization based on the individual and collective needs of the entire family unit. Simple advice pertaining to the need for balance may suffice for some families; however, for others, additional techniques for restructuring are required as evidenced by literature content and focus. We trust that the reader will determine his or her own needs while reading the information we have been able to glean from the literature review.

We have divided the review into four sections: Literature that pertains to (1) knowledge, (2) skills, (3) support, and, (4) attitudes. The first section will focus on the importance of, need for and results of knowledge. The section addressing skills will concentrate on research findings based on skills training programs for parents. The third section, support services, will focus on the relationship of support and empowerment. And lastly, the section on attitudes will review the importance and impact of attitudes of both professionals and parents, alone and in consort or partnership with each other.

Limitations Within the Literature

Despite the impressive amount of available literature pertaining to disability and its effects on the family system, many of the results assigned to specific studies are described as "inconclusive," due, some say, to the lack of quality and high standards, poor research design, inadequate reporting of essential facts, including essential characteristics of subjects such as gender, age and even the exact nature of the disability (Buscaglia, 1983). Perhaps the most crucial deficiency in the literature reporting research results was the lack of the use of control groups and measurement devices (Murphy, in Roberts, 1982; Buscaglia, 1983). Populations with disabilities are quite often compared only with each other. The importance of such control groups cannot be underestimated as they enable the researcher to evaluate (hypothesize) the specific effects of treatments or experimental variables. The presence of control groups, however, does not always guarantee meaningful comparisons: oftentimes, when researchers did use a control group, they failed to report how their samples were selected or to identify the criteria used for matching subjects. Some studies used vague terminology when reporting changes or advances made through certain interventions. For example, a child´s behavior "improved," or parents "benefitted." For the purposes of this paper, many studies were reviewed, but not included here because of the evidence of limitations such as those addressed above.

KNOWLEDGE

In a study evaluating the impact of stress in families with an infant with disabilities, Beckman (1983) concluded that professional´s views of parent involvement in intervention programs need to be expanded to include knowledge about the potential impact of the child on the family. Such an expanded view was regarded as especially important at a time when parents are being encouraged to care for their children at home.

Featherstone (1980) echoes the same sentiment when she writes, "Parents need information about their child´s problems," (p. 178) as does Dickman (1986) when he wrote, "It is better to know, even if it is a shock, so you can do (p. 30). Featherstone furthermore states that at the most basic level there is the need for information about the initial diagnosis, and beyond that, the origin of the disability and its implications for the child´s life. Several parents have expressed their personal agonies related to not knowing what was wrong with their child (see for example, Dickman, 1986; Kushner, 1983; Barsch, 1968) very often because of an "overprotective," insensitive or unknowledgeable physician, and the resultant feelings of having lost precious and valuable time in getting the services and support needed. Most parents are aware of their child´s problems before anyone else; however, they need adequate, candid, clear and appropriate information before they can begin the processes of pro-action and intervention on behalf of their child and themselves.

In his book, *Special Children, Special Parents,* Murphy (1981) devotes one chapter to the theme of learning. In it, he quotes several parents who have had positive experiences with professionals and agencies, thereby stressing the importance of information. One parent shared the following to which we again add our bracketed variables of empowerment:

> They included me in the activity planning right from the start [attitude, knowledge, skills]. She not only did her own job but always tried to keep me informed of all the other services and agencies we´d be needing. She´d go out of her way -- she was really concerned [knowledge, attitude].
>
> The clinic shared everything with us -- what they knew about Margie, giving us copies of important records, treating us with respect [knowledge, attitude].
>
> She helped me feel better about my son and about myself without kidding anybody -- I mean, she helped us see the limits, too. She helped me to get beyond "whose fault" to "nobody´s fault" [attitude, support]. (Murphy, 1981, p. 149)

Wolfensberger (1983) in discussing his normalization-based approach to intervention encourages counselors to deal with exceptional parents/families as equals, thereby encouraging the relinquishment of the "expert" role. He points out unconscious assumptions held by many professionals when he wrote the following:

> Sharing of all available information surrenders control and

> the professional workers [feel they] should have control of the situation. Knowledge is power, and when one person achieves knowledge equally with another person, the previously more knowledgeable person surrenders or loses his or her superior power position. (Wolfensberger, 1983, p. 20)

Wolfensberger explains that some professionals need control because of some personal insecurity rather than an ideological belief that pertains to a service relationship. Other professionals assume that clients [parents] "are stupid and simply would not understand the information" even if it was given (Wolfensberger, 1983, p. 20). Wolfensberger contends and bases his contentions on his own empirical research, that the contemporary public is comprised of "remarkably well-educated citizen-consumers whose citizenship status in society gives them the right to know, the right to make up one´s own mind, know about and deal with one´s own [family] condition . . . It is one´s right," he says, "to suffer if one is told unpleasant realities that one has either asked for of purchased in the form of information" (p. 20 - 21). Wolfensberger supports a Parent Education Model [skills and knowledge] rather than "mentalistic counseling." This education, he believes, should include a support network element as well as guidance and information specific to each family (emphasis added).

One solid and useful strategy addressed in some of the literature is the need for education with regard to developmental and adaptational challenges in the present and the future (Featherstone, 1980; Murphy, 1981; Buscaglia, 1983; Coppersmith, 1984; Dickman, 1986). When parents possess knowledge about potential problems (such as guilt, loneliness, self-esteem, burnout) and specific issues (such as sexuality, siblings, education, employment), they very often feel better prepared and hence, empowered when actually confronted with the need to deal with them.

Knowledge can also empower parents when it involves information about legal and ethical rights. To most parents, receiving a medical diagnosis is frightening if not paralyzing (Featherstone, 1980; Dickman, 1986). Several authors, particularly in non-research oriented literature, have discussed basic moral and ethical rights of parents (Featherstone, 1980; Murphy, 1981; Turnbull & Turnbull, 1978; Buscaglia, 1983; Dickman, 1986). An underlying theme in much of their writings is the right to information. Buscaglia (1983) addresses the "right to know" issue more specifically when he posed the following rights of parents:

> - The right to sound medical knowledge regarding their child's physical or mental problem
> - The right to some form of continual re-evaluation of their child at definite periodic intervals and a thorough, lucid explanation of the results
> - The right to some helpful, relevant and specific information as to their role in meeting their child's special physical and emotional needs
> - The right to knowledge of the educational opportunities for their child and what will be required for later admission to additional formal schooling
> - The right to knowledge of community resources available for assistance in meeting the family's needs, intellectual, emotional and financial
> - The right to information about rehabilitation services in the community and resources available through them
> - The right to some hope, reassurance and human consideration as they meet the challenges of raising a child with special needs
> - The right to good reading material to help them acquire as much relevant information as possible
> - The right to some interaction with other parents who have children with disabilities
> - The right to actualize their personal rights as growing, unique individuals, apart from their children. (p. 102)

SKILLS

Perhaps the largest volume of research is couched in the area of skills training or the practical application of knowledge. The past decade has seen the rapid increase of programs serving individuals with disabilities and their families. Research has established the effectiveness of various techniques, methods and curricula for early intervention and for working more closely with parents to remediate the effects of handicapping conditions (Linder, 1982).

One such program is called Parent Effectiveness Training (PET). It is based on the premise that "everybody wins" in contrast to the "win-lose" aspects of other authoritarian or controlling methods. Winning is clarifying what individuals (parent, child, mate, teacher, etc.) can and cannot accept in themselves and in the behavior of another. What is negotiated in parent-child relationships is power. In the authoritarian model the parent has all the power and the child has none. In the permissive model, the child is given most of the power the parent gives up. In the Effectiveness Model, nobody loses: the power is negotiated and therefore shared by both the parent and the child with a clear separation between personality and performance (for example, "I love you but that does not mean I accept your behavior"). PET succeeds if a parent overtly or covertly wants to define the relationship with a child as egalitarian. Locus-of-control issues, then, would be lessened since power would be shared and communication and guidelines for behavior would be clear. This infers that empowerment is experienced by both parent and child. The issue of parental authority (i.e., child obeying parent) is a traditional, situational relationship built into PET and is addressed as a function of responsibility for the parent as the ultimate caretaker for the child. Parents, as such, are responsible for and entitled to making certain decisions that are perceived as in the best interest of the child and the family unit within which that child holds membership.

Just how effective is the PET program? Rimm and Masters (1977) reviewed the literature concerning the effects of PET on parents and their children. Much of the research was considered inadequate by a number and variety of methodological criteria, raising questions about its preventative intervention strategy. They concluded with strong feelings that PET should make a systematic program of research and evaluation and include this as an essential part of training organization (Rimm & Masters, 1977, p. 108).

In another study, Gordon (1977) indicated that parents utilizing effectiveness training showed: (a) an increase in trust, self-esteem, and confidence in themselves and in their parental roles; (b) increased trust and acceptance of their children; (c) increased understanding of their children's behavior; (d) improvement in regard to increasing democratic attitudes and decreasing authoritarian attitudes and practices; (e) reduced number of problems with their children and an overall reduction in anxiety.

Several other studies that examined parent effectiveness training or specific skill training came to similar conclusions: Programs that respect the dignity of parents and children, and that provide adequate knowledge, reinforcement, support and follow-up in the development and transfer of skills into the home environment work (Nay, 1975; Eyberg & Johnson, 1975; Linder, 1982; Minor, Minor & Williams, 1983; Garfield and Bergin, 1978; Patterson, 1974; Salzinger, Feldman & Portnoy, 1970; Rinn, Vernon & Wise, 1975).

In their book, The Unexpected Minority: Handicapped Children in America, (1980), authors Gliedman and Roth include a section on P.L. 94-142 which calls for the active involvement of parents in almost every stage of the school's formal decision-making process from the initial diagnosis to the construction of an Individual Education Plan (IEP). This would include choosing the least restrictive environment for their child's education. "Active participation" is a term that the authors view as unclear within the law. The phrase, they contend, is often misinterpreted by some to mean that "the parents are expected to cooperate with the recommendations of the school's experts, and to do their utmost to fulfill the obligations of the "sick role" (p. 183). This issue could have been included in this paper's sections on Knowledge or Attitudes as it deals with the parental right to information and the need for change in the attitudes of some professionals and in the levels of assertiveness of some parents. We have included this discussion in the Skills section because we believe that parents have the right and some the need to be trained as self-advocates and partners in the planning process of their child's education. Including the right in P.L. 94-142 does not necessarily guarantee that all parents have the skills necessary to become powerful, well-informed advocates. Writer Dickman (1986) in his book entitled, One Miracle at a Time, presents some excellent guidelines in the form of checklist questions parents can ask themselves about the IEP's goals and objectives, program details, related services and placement in the "least restrictive environment." In addition, he includes a very helpful chapter on IEP negotiation tips for parents from parents.

In other sections of The Parent Empowerment Packet (PEP), we have included a paper on "Parent and Professional Partnerships" and some worksheets for keeping records such as names, addresses, or questions asked and answers received.

ATTITUDES

A comprehensive review of the literature linking attitudes of professionals and their impact (both negative and positive) on the process of empowerment is certainly beyond the scope of this paper; however, it must be addressed as it is an important part of the empowerment paradigm (see Figure 1). Although families that have a member with a disability operate under the same influences as "typical" families, they are likely to have greater involvement with schools, teachers, physicians, social service agencies and other professionals and usually have more limited social contacts (Farber, 1970). They must also cope with socio-cultural stereotypes and attitudes regarding the disability (Turnbull and Turnbull, 1978; Featherstone, 1980; Murphy, 1981).

The behavior and attitudes of others, especially professionals, are very powerful and deserve a great deal of attention as they seem to influence elements such as individual beliefs and self-concept, problem-solving, social contact, morale, etc. (Crnic, Freidrich, and Greenberg, 1983). They may even affect the individual and familial response/attitudes to the exceptional child.

One major flaw in the literature seems to be the "common unwillingness or incapacity on the part of the professionals to speak or write in simple lay people´s language" (Wolfensberger, 1980, p.22). Much of the literature, even that supposedly written for family members, seems to be couched in academic langauage or jargon. This criticism infers that a great deal of rich information may be lost to the layperson in a smokescreen of verbiage.

Another criticism of the literature, alluded to earlier, is the evidence of the "prejudicial attitudes" of society and professionals toward people with disabilities and their families in much of what is available. This oppressing attitude was clearly captured by an anonymous writer in A Voice for Retarded Citizens, a publication for retarded citizens and their families. This article addressed the issue of the placement of expectations upon exceptional parents by others and by themselves:

> . . . The parent of a non-handicapped child may skip a monthly PTA meeting and no one may think much about it, while the parent of the handicapped child may be said to be uncaring and hard to reach if s/he skips a monthly PTA meeting. A working parent who tries to do house chores at night and attend to the children may feel harried, may scream at the kids or perhaps even break into tears. When the parent of a handicapped child does these things, s/he may be said to be emotionally out of control and perhaps, even in need of psychiatric help. A great many couples get divorced, but when a couple with a handicapped child get divorced, it is said that the child ruined the marriage. Parents may proudly claim that their daughter will be the first woman president, and people may consider this to be somewhat amusing but certainly not totally inconceivable. When other parents say that some day their handicapped daughter will walk, they may be called unrealistic, unaccepting, and possibly, in need of counseling.

Certainly, expectations like these, whose reality is substantiated by other writers (such as parent/authors like Featherstone (1980) and Turnbull & Turnbull, (1978) have a detrimental and "dis-empowering" effect on parents and families.

The most significant attitudinal change deemed necessary for professionals in much of the literature is their tendency to hold stereotyped expectations and assumptions regarding parental grieving stages. These assumptions bring with them the risk of "pigeon-holing" parents into a stage dictated by theory even when these parents may be coping and adapting successfully to their exceptional situation (Blacher, 1984). Allen and Afflich (1985) suggest that professionals abandon the stage models for grief specifically and instead carefully re-evaluate individual and family coping responses. Recent literature on family coping with stressful events suggests that a wide variety of variables influence stress and adaptation in families and individuals and should be dealt with individually. This wide range of variables allows professionals and parents themselves to understand the nature, intensity and duration of stress responses, the parents´ perceptions of the child, and their ability to find meaning in their situation and restore a sense of control over their lives. Simple knowledge of such coping strategies may help alleviate distress and helplessness as well as help parents maintain a realistic view of themselves, their own situation, and their child´s condition (Allen and Affleck, 1985). The authors seem to be suggesting a more humanistic approach linked to personal empowerment, although much of the literature shows that parents feel they have more often been treated as patients . . . "surrendering to the professional´s conception of parental priorities and duties" (Gliedman and Roth, 1980, p. 148).

Until recently (particularly since the passage of P.L. 94-142), parents had seldom been involved in assessment or treatment plans and often felt as though things were being said and done behind their back. Even though that Law has been in effect since 1975, many parents still aren´t aware that it exists (Dickman, 1986) and many others feel inadequately educated and prepared for actualizing the full participation expected of them. Certain professionals are content with assuming the powerful "expert" role, and overtly or covertly assume a "father-knows-best" (and in this case the professional is that father) attitude and certain parents are equally as content in assuming the more passive, submissive and powerless role (Gliedman and Roth, 1980).

Hopefully, there is some indication that both distressful attitudes are changing, but change rarely comes easily. Professionals need to understand that parents know their child better than anyone and, regardless of the fact that there is a Law demanding it, their full involvement is vital to the child's education. They also need to understand that many parents need support, reinforcement and the actual skill development that will enable them to become partners with the school system and that, furthermore, they have a responsibility to provide that.

Parents have certain responsibilities, also, and some do pertain to changing their own attitudes. Some parents have never let go of their own guilt and feel that the presence of a child with a disability is the result of something "bad" they did (or didn't do); kind of an inappropriate application of the old saying, "You reap what you sow." Any difficulties encountered while raising the child then is their "punishment" which serves to assuage the guilt. Aside from being totally inaccurate, this attitude is perhaps one of the most self-defeating and destructive for everyone involved, particularly the person holding it. It may require lots of help and outside support, but the sooner the person realizes that producing a child with a disability is nobody's fault, the more empowered and free that person will be. In his book entitled, When Bad Things Happen to Good People, Kusher (1983) wrote that "'What did I do to deserve this?' is an understandable outcry from a sick and suffering person . . . [however] The better question is 'if this has happened to me, what do I do now, and who is there to help me?'" (p. 60-61).

Some parents are quite aware of what their rights are under the law as it pertains to their child's education or treatment; however, if there is an occasion when these rights seem to be or are in jeopardy, the thought of "fighting the system" becomes overwhelming. Fear is a real emotion and many parents do feel frightened and intimidated by the huge and powerful bureaucracies they must confront. An attitude of powerlessness is indeed a difficult one to fight, but fighting is necessary for our own survival regardless of the presence of a child with a disability. By giving up our own sense of control, we give up our own power, and therefore, our own freedom and sense of personhood. We effectively throw away the very core of our being when we relinquish our right to act with purpose and determination. We may stumble, and we may fall often in our attempts at learning how to cope and deal with systems. But it may be helpful to remember that taking our first steps as a baby was accomplished only because we always got up after we stumbled and tried the process again and again until we were finally able to do it under our own control. How true the saying that "for every step forward, we take two back" and how much easier it is when we´re able to add, "and that´s OK."

The literature emphatically supports the notion that parents seek out and take advantage of whatever resources are available to them in an effort to reduce stress on themselves and the family, thereby increasing their ability to cope. Parental health, energy, and morale involve physical and emotional well-being prior to and during a stressful event (Crnic, Friedrich and Greenberg, 1983). Acquiring knowledge, skills and attitudes that empower parents and their families is necessary for maintaining that health, energy and morale, but we believe that support from others is equally as vital.

This next and final section will review the literature that addresses this component of the empowerment process.

SUPPORT

The direction of family research from the 1970´s perspective which concentrated in eight general areas: behavioral management studies; continuum of care studies; deinstitutionalization effects; demographic studies; family dynamics and adjustments; institution studies; parent attitude studies and sibling studies has changed (Rowitz, 1985). Three new areas of study for the 1980´s include: (1) parenting (Blacher, 1984); (2) life-cycle studies (Suelzle & Keenan, 1981) and (3) Social Support Networks (O´Conner, 1983; Intagliata & Doyle, 1984).

Social support consists of verbal and/or non-verbal information or advice, tangible aid, or action that is proffered by social intimates or inferred by their presence and has beneficial or behavioral effects on the receipient (Gottleib, 1983). Gottleib differentiates social network from support system in that a system implies a closed institutional arrangement. A network, he writes, evolves, has a history, and is affected by extrafamilial influences. The network concept acknowledges that each family member has a history and changes through the life of the family. The "family" then, becomes and works as a support for each member, including the parent. Gottleib sees great stength within the family system itself for support of it´s members. Caplin (in Rowitz, 1984), a psychiatrist, cited nine potential functions of the family network [including extended family]: 1) the family as a feedback guidance system; 2) the family as a source of ideology; 3) the family as a collector and disseminator of information; 4) the family as a guide and mediator in problem-solving; 5) the family as a source of practical service and concrete aid; 6) the family as a haven for rest and recuperation; 7) the family as a reference and control group [reality base]; 8) the family as a source of validation and identity, and 9) the family as contributor to emotional mastery. Though much research has yet to be done, Rowitz sees these functions as "fertile territory" for investigation. We see these functions as vital in attempts to comprehend empowerment and assess existing resources.

Another important resource tapped by many families involves networking (see PEP section on "Support Groups"). Social networks of exceptional parents provide powerfully supportive relationships that may facilitate positive adaptations through resource sharing, brainstorming and support. Investigations have also shown that social relationships and respite support have a tremendously positive impact on parental functioning as a whole (Friedrich and Friedrich, 1981).

In 1981, Suelzle and Keenan conducted a study addressing the use of support networks by parents of retarded children. They collected survey data cross-sectionally on 330 families and found that parents of younger children utilized more support networks and were supportive of "mainstreaming," whereas parents of older children had less support and were more isolated. They reported that families that utilized support networks had significantly more positive relationships within the family and between the parents (Crnic, Greenberg, Ragozin, Robinson, and Basham, 1983).

Networking, apparently, is often being done informally, so informally that much of the process has gone unrecorded within the literature. Theirfeld (1984), for instance, submitted a brief article to the Journal of College Student Personnel in hopes of encouraging other parents to form their own support networks in the workplace. Thierfeld cites networking as an effective and necessary tool for pooling resources and obtaining information and support. Her article outlined an informal network formed at the University of Rhode Island for exceptional parents who were employees of the University. The Rhode Island Department of Special Education estimated that at least "360 employees of the approximately 3,000 staff and faculty members had children with some disability." These parents represented various stages of coping with the disabilities. The outcome of informal networking was the formation of a support group called Dealing with Disabilities: A Parent's Point of View, which included a mixture of single, foster and traditional parents. The group consisted of "peer experts," sharing resources, support and a forum for airing emotions. Most important, said the author, was the availability of parents [veterans] who had already "lived through" a diagnosis of disability in their child and managed to get through the early stages of coping and managing and their contributions of experience and insight to parents of recently diagnosed children. Shared information was practical, ranging from recommended dentists and neurologists to books and special toothbrushes. From this informal network of support and learning, respite and emergency hotlines were established. An undergraduate Child Development major was utilized for child care during their meetings, who was able to offer practical information and respite for parents.

Wolfensberger (1983), in a normalization-based outline of guidance for exceptional families suggests that professional counselors can help [to empower] families by giving directive advice when asked, or if one feels strongly enough about a potential directive. He believes "it is culturally normative to state one's opinions to people" (pg. 20). This advice, he asserts, should include spelling out the limitations and biases that may be involved in any given solution as well as reasonable alternatives. Active support, wherein the counselor becomes involved in a pycho-educational relationship with the family, "may help to motivate and/or enable them [the family], as individuals or within voluntary associations, to function in a variety of capacities so as to bring about positive policy and community changes" (p. 20). Wolfensberger suggests that counselors be sensitive to myths and to their own common sense with regard to judging how much/what type of information a family needs and will be able to handle. Treating the family honestly and with respect, he maintains, will do a great deal to enable [empower] the family (Wolfensberger, 1983).

Family therapy has also been addressed as a source of support in much of the professional literature. Turner (1980) suggests that the overall goals of family therapy for the exceptional family should first be geared toward educating the family to deal with present and future problems. Often, he states, exceptional families are dealt with as pathological, when in fact, they are merely in need of information and support which is realistic to request from a family therapy experience. Those areas that Turner suggests be addressed in a family therapy situation include: acceptance of the identified child´s diagnosis and it´s realistic implications on the family; shifting from short-term goals to long-term planning (not specific); increased education regarding the handicapping condition including misconceptions; appropriate display of feelings regarding the situation and the child as well as teaching coping strategies; practice in relating as a family; general improvement of child rearing practices; increased family involvement with the care of the identified child and shared responsibility for meeting the needs of both the children and parents. Turner summarized that the family therapist can best help support the exceptional family by teaching problem-solving behaviors on the part of all family members.

Perhaps the most significant theme within much of the "support" literature, is that of respite care. Joyce, Singer & Isralowitz (1983) evaluated families over a four-month period in regard to the impact of respite services on their family relations, social activities, emotional and physical strains and plans for institutional care. Respite care was shown to have a positive impact in all of these areas. Families caring for younger children viewed the services as more helpful than parents caring for older children or adults. Thirty-two families were evaluated for the in-home respite program. Mean age of the disabled children/adults was 12.9 years, the age range was 1-29 years. The families used an average of 88.5 service hours each during the study period. Service hours ranged from 4 - 437 hours. Level of care was determined through the use of a 15-item instrument which addressed three areas of concern: independent functioning, communication development, and emotional development. Families, regardless of the disability, were free to request as many hours of service as they thought were needed.

According to the parent responses, respite care had a positive effect on family relations. 53% of the parents either strongly agreed or agreed that they had been relating better to their disabled son or daughter since receiving respite care services. When asked whether respite care had helped to relieve family stress, 68% agreed strongly or agreed and 16% disagreed. The respite care specifically enabled the non-disabled members to spend more time with each other, they reported. Respite care was credited for: increasing social activities; allowing parents/families to make plans ahead of time [rather than just on a "good" day] -- they reported doing things that they never felt they could have without the respite such as travel or stay away for a few days. In general, it seemed the type, amount and quality of leisure activities significantly increased. The results of the study revealed that 95% of the parents felt that respite care helped relieve physical and emotional exhaustion; 75% said it helped them feel less physically tired; 77% said they felt less guilty leaving their child. 86% strongly disagreed with this statement: "although respite care services have been a little helpful, I could get along just as well without them." 91% agreed that respite care helped them avoid institutionalizing their child.

Joyce, Singer & Isralowitz (1983) concluded that the overall results provided empirical evidence that parents using respite care services see these services as helpful in improving family relations, increasing social activites and alleviating physical and emotional stress. No relationship was demonstrated between the number of hours of respite care received and the quality of life score, and therefore led the authors to assert that a moderate intervention can do a great deal to alleviate familial stress.

Summary

In concluding this review of the literature on empowerment, it seems clear that more and more professionals are becoming interested in addressing the issue of parental empowerment. Though one is able to see that positive behavior changes may be achieved by providing knowledge, changing attitudes, teaching skills and lending support, no "cookbook" solution for parents is available at this time. Much of the literature is gathering dust in the archives, journals and microfische. What seems equally clear is the need to find some way to translate, and therefore, to share much of the research findings with those consumers that could really use it -- parents of children with disabilities.

Several observations have emerged through this review of the literature:

1) Exceptional families and ways of helping them become more self-empowered are idiosyncratic. Perhaps, families are best served by a multi-faceted program/ guide to empowerment that acknowledges each family's uniqueness.

2) Funding, though sparce, might better be utilized by professionals in finding ways to translate and transport existing research/findings to consumers rather than only in professional journals.

3) Attitudes of both parents and professionals need to be addressed if parents are to gain and maintain an internal locus of control. Stereotypes of parental helplessness need to be dropped by both sides, and replaced with respect and cooperative problem-solving.

4) Information resources need to be made more readily available to parents, for in some cases, information is all that is needed to empower.

5) Skills training is a necessary component to many empowerment state-gies. What seems most effective, albeit time consuming and expensive, is one-on-one training. Perhaps funding could be utilized for training people in support networks to become "peer experts."

6) Support networks and respite care are effective ways of dealing with stress in families affected by the presence of disabilities.

7) Family therapy can be a useful means of empowering the exceptional family through education and communication skills training. The family has the potential of acting as it´s own support network once empowerment is achieved, that is, internal control realized.

Family therapists have the knowledge and skills to contend with the systemic organization of the family. But what of the family with a child who has one or more disabilities? How does the family adapt to, cope with and work through a component of that system that may not change? One method may very well be that of helping individuals gain control over their own lives -- empowerment.

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PARENT EMPOWERMENT BIBLIOGRAPHY

by Linda Oliva and Patricia A. Shank, Ph.D.

The books listed below are highly recommended for parents looking for literature that empowers rather than discourages. Many were written by other parents who were interested in sharing their experiences and insights.

The list is far from complete. You may have some favorites that haven't been included here, so we've added some blank pages for you to write them down. Some books and magazines you read may direct you to other resources; write them down, too. When visiting your local library in search of a particular book, bring the publication information (title, author, publication date and publisher) with you. Your search will be a lot easier.

Keep an eye on book reviews included in such resources as the Exceptional Parent Magazine. The reviewers are typically selected because of their expertise in or sensitivity toward a particular subject.

You might also want to contact some publishing companies for their most recent catalog of books that pertain to the subject you're interested in. Your local librarian should have the complete mailing address for all publishers.

NOTE: See PEP section on SIBLINGS for additional helpful resources.

A Difference in the Family: Life with a Disabled Child

Helen Featherstone
Basic Books, New York, 1980

This sensitive and revealing work tells how it really feels to raise a child with a severe disability. Featherstone, a parent and an educator, provides an important consciousness-raising guide that can help parents feel less alone and professionals appreciate the problems and pleasures of those who live with and love a child who is different. She also includes information about families in general and how they endure any serious disruption.

A Handbook for the Disabled: Ideas and Inventions for Easier Living

Suzanne Lunt
Charles Scribner & Sons, New York, 1982.

A practical guide that shows what is available, names and addresses of manufacturers and suppliers, as well as references to other sources of information for people with disabilities.

Although . . . Those Who Overcame

Barbara Gosline Smith
Padre Publications, 1981.

This unique collection of mini-biographies of people who overcame their disabilities is indexed by specific handicaps.

An Easy Guide for Caring Parents: Sexuality and Socialization

Lyn McKee and Virginia Blacklidge
Research Press, Prairie Village, KS, 1981.

Written specifically for parents of individuals with mental handicaps, this booklet provides a comprehensive overview for parents to help "guide their sons and daughters toward greater responsibility, sexually and socially." The authors recognize parents as the "most influential teachers" and offer practical advice spanning childhood to adulthood.

Behavior of Exceptional Children

Norris G. Haring, Editor
Charles E. Merrill, Columbus, OH, 1979.

This text is useful to parents who want to learn about the field of special education. It reviews the traditional categories of disabilities and presents stages of development. The book presents descriptions of model programs, profiles of outstanding practitioners and theoreticians of special education, and descriptions of the major parent and professional organizations.

Cara: Growing with a Retarded Child

Martha Moraghan Jablow
Temple University Press, Philadelphia, 1982.

The mother of Cara tells the story of loving and raising her daughter who is retarded. Cara was one of the first infants to be enrolled in an early intervention program designed to stimulate development. The book is a sensitive and touching story of the pain and triumphs that Cara brought to the family.

Children and Adults: Activities for Growing Together

J. Braga and L. Braga
Prentice-Hall, Inc., Englewood Cliffs, NJ, 1976.

This book was written for parents, grandparents, teachers, babysitters, -- "any one touching the lives of children." It was designed to help children (birth through age six) and adults grow together. Although not written necessarily for children with disabilities, the practical activities presented are based on general principles of growth and development, and most emphasize social and emotional development. There is a good section that lists a variety of resources.

Coping with Chronic Illness: Overcoming Powerlessness

Judith Fitzgerald Miller
F.A. Davis Company, Philadelphia, 1983

This book is written primarily for nurses to enable them to alleviate patients´ perceived lack of control. The concepts of coping and powerlessness are explored in the first section of the book. Part 2 includes a discussion of powerlessness during vulnerable periods of human development. Specific chronic health problems and patient perceived control are addressed in Part 3. The final section of the book suggests strategies for nurses to use to alleviate patients´ feelings of powerlessness. Some helpful strategies for parents here.

Coping with Crisis and Handicap

Aubrey Milunsky, Editor
Plenum Press, New York, 1981.

This book is the proceedings of the National Symposium on Coping with Crisis and Handicap. The symposium evolved as a consequence of the multidisciplinary involvement of those concerned about the care of dying and handicapped children. The topics that are addressed include medical ethics, the bereaved parent, sexuality issues, legal rights of handicapped, sensitive education of children about handicapped peers and management of autistic children.

Educating Handicapped Children: The Legal Mandate

Reed Martin
Research Press, Champaign, IL, 1979.

This easily understood book discusses the various laws and court cases mandating education for children with a disability. The book offers clarifications of the elusive terms and concepts in the legislation such as "appropriate" and "least restrictive environment."

Families Against Society

Rosalyn Benjamin Darling
Sage, Beverly Hills, CA, 1979.

The author reports how parents of children with birth defects recognize the worth and value of their children and go on to become "parental entrepreneurs," advocates for the services that their children require.

Families of Children with Special Needs: Early Intervention Techniques for the Practitioner

Allen A. Mori
Aspen Publications, Maryland, 1983.

This source book provides practical information to professionals who must answer the difficult questions parents ask about their exceptional children. It provides information to assist professionals in establishing the parent-professional partnership necessary to meet the diverse and complex needs of exceptional children. Specifically, the book explores issues about the child development process, the impact a handicapped child has on the family, parent-professional partnership and the rights and responsibilities of families of handicapped children.

Family Strengths: Positive Models for Family Life

Dr. Nick Stinnett, Dr. Barbara Chesser, Dr. John DeFrain and Dr. Patricia Knaub, Editors
University of Nebraska Press, Lincoln, 1980.

This book is the proceedings of the National Symposium on Building Family Strengths, an organization committed to enriching family life. The readings represent diverse approaches to building family strengths including descriptions of existing programs, proposed family social policies, review of family life education, sharing research information and discussion of methods and techniques for building family strengths.

Family Survival: Coping with Stress

Parker Rossman
The Pilgrim Press, New York, 1984.

This book holds that no matter what kind of family we have, we all need support systems to replace the disappearing kinship system. The book offers step-by-step guidelines for developing effective support networks.

Family Stress, Coping and Social Support

I. Hamilton, A. McCubbin, Elizabeth Cauble & Jean M. Patterson, Editors
Charles C. Thomas, Springfield, IL, 1982.

This book reflects research which extends beyond a focus on family stress alone to an understanding of how families succeed in managing life's hardships. Coping and social supports are major themes throughout the book.

Helping Professionals Connect with Families with Handicapped Children

Kathleen Devereux DeLuca and Sandra Cohen Salerno.
Charles C. Thomas Publisher, Springfield, IL, 1984.

PEP

This book provides professionals with insights, skills and practical suggestions related to working with families. The underlying assumption of the book is that it is not "good" or "nice" or "worthwhile" to work with the family of handicapped child -- rather it is vital. The authors advocate that professionals acknowledge the incomparable contribution that well-supported and informed family members can make toward the fulfillment of a child´s potential. The book serves as a link between theoretical understanding and practical application of general and specific recommendations for working with family members.

Home Care for the Chronically Ill or Disabled Child

Monica Loose Jones
Harper and Row Publishers, New York, 1985

This manual and sourcebook for parents and professionals was written by the mother of a child who was born with a rare neurological illness. She has combined research and her own experiences and provided an excellent resource for other parents who want to care for their chronically ill or disabled child at home. The book is packed with practical and empowering information on any number of topics.

Hope for Families: New Directions for Parents of Persons with Retardation and Other Disabilities

Robert Perske
Abingdon, Nashville, TN, 1981.

This helpful, honest book deals simply and honestly with parents´ feelings, fears and hopes. The book is full of optimism, humor and sound advice.

How to Write an IEP

John Arena
Academic Therapy Publications, New York, 1978.

This clear handbook provides useful information on the process of developing Individualized Education Plans for children with disabilities.

Learning Can Be Child´s Play: How Parents Can Help Slower-Than-Average Preschool Children Learn and Develop Through Play Experiences

June Mather
Abingdon, Nashville, TN, 1976.

Suggestions and guidelines for play activities that can start in infancy and continue through early childhood are presented.

Learning to Live with a Disability: A Guidebook for Families

Institute for Information Studies, 1980.

This booklet provides strategies for coping most effectively with a disability thereby minimizing its disruptive impact on the family.

Let Our Children Go: An Organizing Manual for Advocates and Parents

Douglas Biklen
Human Policy Press, Syracuse, NY, 1974.

This handbook offers suggestions for parents and others advocating for children on how to change the system when the child is not getting his or her needs met adequately.

Living Fully: A Guide for Young People with a Handicap Their Parents, Their Teachers and Professionals

Sol Gordon
John Day Company, New York, 1975.

The author, a psychologist, professor and lecturer, has assembled a collection of articles that provide constructive and honest guidance. The first section of the book offers young people who have disabilities supportive and friendly advice on how they can best achieve full and happy lives. The second section offers information for families on a wide range of aspects of life with a family member who has a disability. This section includes a "Bill of Rights for Parents." In the third part of the book, suggestions are offered to professionals.

Meeting the Challenge of Disability and Chronic Illness: A Family Guide

L. A. Goldfarb, M. J. Brotherson, J. A. Summers, and A. P. Turnbull
Paul H. Brooks, Baltimore, MD, 1986

This book addresses the common impact or effect of disability and illness on families. It focuses on the process of problem-solving which the authors present as involving the identification of family values and resources, and then following a step-by-step method for finding solutions to the issues confronting the family. Each chapter includes a variety of excellent exercises designed for family use, either individually or as a group.

More Than Sympathy: The Everyday Needs of Sick and Handicapped Children and Their Families

Richard Lansdown
Tavistock Publications, London, 1980.

This book is written for professionals who work with children with disabilities and their families. The author bases his approach on two assumptions: 1) "forewarned is forearmed" - stressing the need for knowledge, and, 2) "trouble shared is troubled halved" - stressing the need for support. Topics addressed in this book include behavior problems, sex education, play and medical aspects of disabilities.

One Miracle at a Time

Irving R. Dickman with Sol Gordon
Simon and Schuster, New York, 1985.

Here is an outstanding book from parents to parents. It is about "how things are," not how they are supposed to be. Writer Dickman, himself the father of a son with a disability, has compiled and blended the experiences of a number of parents. It offers practical information, advice and emotional support on a wide range of topics.

Ordinary Lives: Voices of Disability and Disease

Irving Kenneth Zola, Editor
Applewood, 1982.
Distributed by Disability Studies Quarterly
Brandeis University
Waltham, MA

This interesting collection of stories, essays, poems and excerpts from books by people who have experienced living with a disability or chronic disease, addresses coping and day to day living. Authors include Christy Brown, Ved Mehta, Flannery O´Connor, Adrienne Rich, Betty Rollin, Alexander Solzhenitzyn Martha Lear, Frances Warfield, Vassar Miller, Harold Krents, Eric Hodgins, and Andrew Potok.

Our Special Child: A Guide to Successful Parenting of Handicapped Children

Bette M. Ross
Walker, Chicago, IL, 1981.

This book, framed in delightful humor, offers practical advice based on the author´s experiences of raising a son with Down´s syndrome. The author writes of effective ways of coping -- at home, at school, with professionals, with relatives, in the community and in the mainstream.

Parents are to be Seen and Heard: Assertiveness in Educational Planning for Handicapped Children

Geraldine Markel and Judith Greenbaum
Impact, San Luis Obispo, CA, 1979.

This handbook provides communication strategies to enable parents to effectively advocate for their children´s best interests. Topics addressed include non-verbal and verbal communication, note-taking and listening.

Parents as Playmates: A Games Approach to Preschool Years

Joan Millman and Polly Behrmann
Human Sciences Press, New York, 1979.

This creative collection of games is designed to help parents "turn ticklish times into enriching ones" for themselves and their preschoolers.

Parents Guide to Teacherese

Nancy O. Wilson
Special Child Publications, 1981.

The terminology that many teachers use in the process of diagnosis and remediation of a child's disability is defined in a straight forward manner in this sourcebook.

Parents of Exceptional Children

William L. Heward, Jill C. Dardig & Allison Rossett
Charles E. Merrill, Columbus, OH, 1979.

This book is designed to teach professionals to utilize parents as equal partners in dealing with children with disabilities. An extensive discussion of behavior management and home management is presented.

Parents on the Team

Sara L. Brown and Martha S. Moersch, Editors
University of Michigan Press, Michigan, 1978.

This book explores the implications of parents' active involvement in optimizing the education resources that are available to their child. The benefits of parent-professional partnerships are also presented in this collection of essays written by both professionals and parents.

Parents, Professionals and Mentally Handicapped People: Approaches to Partnership

Peter Mitler and Helen McConachie, Editors
Croom Helm, London, 1983

This book is based on a European seminar on "Approaches to Parent Involvement." It offers an overview of the definition of and rationale for partnership between parents and professionals and gives a number of specific ways in which such a partnership can be realized.

Parents Speak Out: Views from the Other Side of the Two-way Mirror

Ann P. Turnbull and H. Rutherford Turnbull, III, Editors
Charles E. Merrill, Columbus, OH, 1979.

The contributors to this book are parents of a child with a disability as well as professionals working with other families. As professionals they see the weaknesses and strengths of their fellow professionals. As parents, they have experienced the problems encountered by other parents of children with disabilities. They plead for bridging the gap between parents and professionals and relate the need for understanding and assistance to a far greater degree than is commonly provided by professionals.

Prevention in Family Services: Approaches to Family Wellness

David R. Mace
Sage Publications, Beverly Hills, CA, 1983.

These proceedings of the 1981 National Conference "Toward Family Wellness: Our Need for Effective Preventive Programs," presents promising new approaches to the services currently offered to families. The book reflects a shift in emphasis from an almost total preoccupation with remedial services to a new goal of matching remedial services with corresponding preventive services. Through detailed descriptions of many different strategies and programs, the book offers a positive and practical approach to the challenges facing marriage and families today.

Professional Approaches with Parents of Handicapped Children

Elizabeth J. Webster, Editor
Charles Thomas, Springfield, IL, 1976.

This book attempts to provide professionals with suggestions to help improve their practice with parents. Contributors are professionals in a variety of fields. Each was asked to state his/her assumptions about parents, to discuss the rationale upon which work with parents is based, to indicate procedures found useful in practice, and to suggest critical issues in work with parents.

Psychological Testing of Children: A Consumer's Guide

Stanley D. Klein, Editor
Psy-Ed Corporation, Boston, MA, 1978.

This collection of articles about psychological testing can enable parents to understand what the testing can and can not accomplish.

Raising the Exceptional Child: Meeting the Everyday Challenges of the Handicapped or Retarded Child

Lawerence Zuckerman and Michael T. Yura
Hawthorn, New York, 1979.

The authors examine typical misbehaviors that may challenge parents of children with disabilities since it is often hard to distinguish which behaviors stem from the disability and which behaviors can and should be controlled. The advice the book offers is based on the Dreikurs approach to child rearing and includes the provision of consistency, structure, routine and fun.

Raising the Handicapped Child

Laura Perlman and Kathleen Anton Scott
Prentice-Hall, Englewood Cliffs, NJ, 1981

This resource book offers ideas, facts and suggestions that parents may draw upon in the process of raising a child with a disability. The topics addressed include coping, identifying medical problems, developing a good self-image, discipline, socialization and planning for the future.

Role of the Family in the Rehabilitation of the Physically Disabled

Paul W. Powers and Arthur Dell Orto, Editors
University Park Press, Baltimore, MD, 1980.

All of the contributors to this book believe that a person's environment can greatly determine the motivation for and effectiveness of treatment. The book focuses on an essential part of that environment -- the family. The basic theme of the book is that health professionals should understand as many influences as possible that can affect the rehabilitation of a person that has a disability. The book is comprised of three sections: (1) Basic Considerations for Understanding the Family, (2) The Family's Reaction to Specific Traumas, and (3) Helping Skills and the Family.

Sara and Allen: The Right to Choose

Jean Parker Edwards
Edwards Communication, 1976.

Especially written for parents, this book presents an uncluttered, straightforward discussion on issues of sexuality. Topics addressed include masturbation, wet dreams, contraception, marriage and parenting. The book includes a chapter on moral and ethical concerns.

Severely Handicapped Young Children and Their Families: Research in Review

Jan Blacher, Editor
Academic Press, Inc., Orlando, FL, 1984.

This book provides a state-of-the-art summary of research conducted on severely disabled children and their families. Part 1 of the volume addresses the issues of family adjustment to the arrival and rearing of a child with a severely disabling condition. In Part 2, the child´s influences on the family dynamics are discussed. Part 3 focuses on family involvement in the educational process.

Solving Learning and Behavior Problems of Children

Mark N. Ozer
Jossey-Bass, San Francisco, CA, 1980.

The author advocates for a system whereby parents and children work together with professionals to identify the child´s abilities and needs in real-life terms and to plan services accordingly. Interviews with children, parents and professionals illustrate how the system can work.

Special Children, Special Parents

Albert T. Murphy
Prentice-Hall, Englewood Cliffs, NJ, 1981.

The author, a clinical psychologist and professor, sensitively explores the thoughts and feelings of parents of children with special needs.

Strategies for Helping Parents of Exceptional Children: A Guide for Teachers

Milton Seligman
The Free Press, New York, 1979.

This book offers practical and sensible guidelines for improving relationships between parents and teachers. The author is very sensitive to the needs and feelings of parents.

Taking on the World: Empowering Strategies for Parents of Children with Disabilities

Joyce Slayton Mitchell
Harcourt Brace Jovanovich, New York, 1982.

This concrete guide offers suggestions to effectively advocate for your child´s need by asserting yourself and enhancing your self-esteem. Specific guidelines for overcoming powerlessness, asserting control, being active in decision-making processes and mobilizing energy are outlined.

The Exceptional Child in the Family: Helping Parents of Exceptional Children

Alan O. Ross
Grune and Straton, New York, 1964.

Written primarily for professionals, this book offers an overview of principles which apply to understanding and helping a family. The book is based on the conviction that the stress and emotional disturbance associated with having a family member with a disability can be minimized if professionals who interact with the family around the child help them adapt to their special situation.

The Human Side of Exceptionality

Dale D. Baum, Editor
University Park Press, Baltimore, MD, 1982.

This collection of articles from popular magazines explores the "humanistic dimensions of handicapping conditions." The book is designed to be used as a supplement in professional training programs and includes commentaries and discussion questions on a variety of disabilities.

The Special Child Handbook

Joan McNamara and Bernard McNamara
Hawthorne Books, Inc., New York, 1977.

The purpose of this book is to guide parents through the experience of raising a child with a disability from the initial recognition of the disability to possibilities for the future. This handbook is based on personal and professional experiences and includes essential information that can assist parents in understanding and dealing with their feelings.

The Technology for Independent Living Guide

Sandi Enders, Editor
Rehabilitation Engineering Society of North America, Bethesda, MD, 1984.

This guide offers information about equipment and technology and their practical application to the everyday life of the individual with disabilities. Includes extensive references to useful publications, resource persons, and organizations that can provide assistance. Also includes a good guide to sources of toys for children with disabilities.

Unraveling the Special Education Maze

Barbara Coyne Cutler
Research Press, Prairie Village, KS, 1981.

The author, a parent, educator, trainer and advocate, states that parents often fail to participate effectively in the education of their child due to inadequate organization of services. She offers strategies and direction to enable parents to become effective advocates for change.

BOOKS OUR FAMILY HAS FOUND HELPFUL

TITLE: ______________________________

AUTHOR(S): ______________________________

PUBLISHER, CITY, DATE: ______________________________

DESCRIPTION:

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The Family System

This section of the PEP reviews some of the concepts employed in systems thinking as these relate to the family.

THE FAMILY AS A SYSTEM

It has become fairly common recently for many human service organizations and professionals (special educators, family therapists, therapeutic recreation specialists, etc.) to view an individual and her or his family from a systems perspective. Although the jargon and concepts inherent in systems thinking is somewhat familiar to some people (parents and professionals), they may not be well understood by everyone.

We've broken this section on systems into two papers. In the first paper, you'll find some questions and answers that help explain some of the basics of systems thinking. The intent here was to simplify some of the ideas and language you'll hear many professionals use when they talk about viewing the family as "a system."

The second paper provides a bit more theory for those seeking it. Undoubtably, there's more to "systems thinking" than what has been provided here so if your appetite has been whetted for more depth, we encourage you to consult the references that follow the second paper.

FIVE QUESTIONS AND ANSWERS ABOUT THE FAMILY SYSTEM

Question: I´ve heard some professionals talk about our "family system." Why is it called a "system"?

Answer: Imagine a mobile suspended over a baby´s crib. Parents usually put them over the crib to brighten up the baby´s environment and to provide some visual stimulation for him or her. That´s the purpose of a mobile. This mobile is made up of several unique and colorful forms that are attached by string or wire to the center of a bar or another form. When you touch one of the forms, the whole unit will move. If you blow on it or there is a breeze in the room, all the parts will "dance." The interesting thing about mobiles is that they move whether we touch them or not. That´s because of the unseen energy in the environment. If you were to hang something heavier on one of the forms, the whole mobile will become lopsided and wouldn´t move so freely. The mobile would lose its its ability to respond to the energy in the environment.

The mobile can be considered a system because it has parts that are connected and interrelated; together, these parts make up the whole mobile and give it its purpose. If we were to remove some of the parts and add others, it wouldn´t be the same mobile. If we were to take the mobile off the baby´s crib and put it into a box, it would still be a mobile, but it wouldn´t be fulfilling its purpose. It would become a non-functioning system.

The family is like a mobile in many ways. Each of the forms can represent the family members. Each member is unique and colorful. The central form can represent the family's values, beliefs and traditions -- those things that hold the whole unit together. Each part of the family is connected to every other part. There are invisible lines, so to speak, that connect them and they are dependent on each other for giving the family its purpose. The purpose of a family is to realize its own growth.

Like the mobile, the family is affected by conditions in the environment -- it, too, will change when one of its members is "touched" in some way. For example, if someone is ill or cries out of hurt or pain, the whole family will be affected in some way. Likewise, if something wonderful happens to one of the members, usually everyone will be able to experience the pleasure and good feelings to some degree. We can see that the family not only is affected by its own environment, but it also affects that environment. For example, if one person is in a rotten mood, it will affect the mood of the other people in the family. One person may stay out of the way of the person in the bad mood, another may try to "fix" it, while another may "catch" the same mood not really understanding why.

Question: **What is meant by the statement, "Family systems are dynamic?"**

Answer: **All** systems are dynamic. The family system is dynamic, also, which simply means it has its own energy and therefore, it is continually "moving" or changing. Because all the members are continually learning, developing and changing, the system will change also. Like the mobile, we may not always be aware of the changes or the energy producing them.

When a new person enters the family system, it might seem lopsided like the mobile was when something affected its balance. Unlike the mobile, which requires something other than itself to remove the "intruder," the family can usually regain its own balance and once again, move freely. How well the family adapts to the changes depends on how flexible and supportive the family environment is to change in general, and how well each member of the family adjusts individually to the changes.

Question: **What does "suprasystem" mean?**

Answer: "Supra" literally means "above." When the term is used in respect to family systems, it means a larger system outside of the family but to which the family is connected. It´s just like the basic system, only larger. A suprasystem to the family can be the extended family, the neighborhood, the community or society. The family is affected by and affects the suprasystem just as it affects and is affected by its own system. For example, the family is affected by (and affects) its relatives´ values, perceptions, beliefs, and traditions. So is the neighborhood and the community and any other suprasystem in which the family is a part.

Question: **Then what is a "subsystem"?**

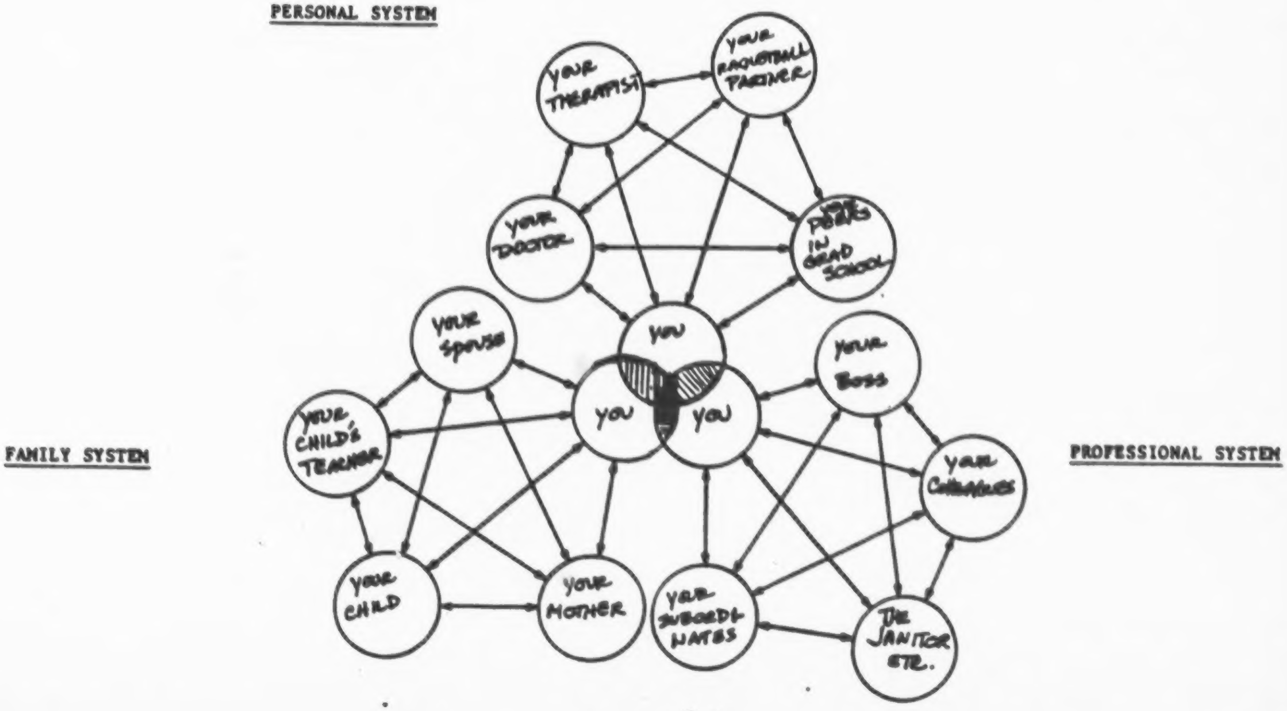
Answer: "Sub" means "under." When the term "subsystem" is used in regard to the family system, it means smaller systems within the family. For example, there is a parental subsystem and a sibling subsystem. Another example is the subsystem of males and the subsystem of females. The family itself is a subsystem of the extended family, the neighborhood, the community, etc. Whole systems are comprised of subsystems that are interrelated. In our mobile, the hanging forms make up a subsystem, the wires holding the forms make up another. The mobile´s functioning is dependent upon the interaction of these two subsystems.

Subsystems give the larger systems their identity. They are meant to work together in order for the suprasystem to function properly. In order for them to do so, there has to be clear and effective communication and ongoing feedback between and among each of the subsystems. Healthy, open and honest interaction between and among all family subsystems is essential to the health of the whole family system.

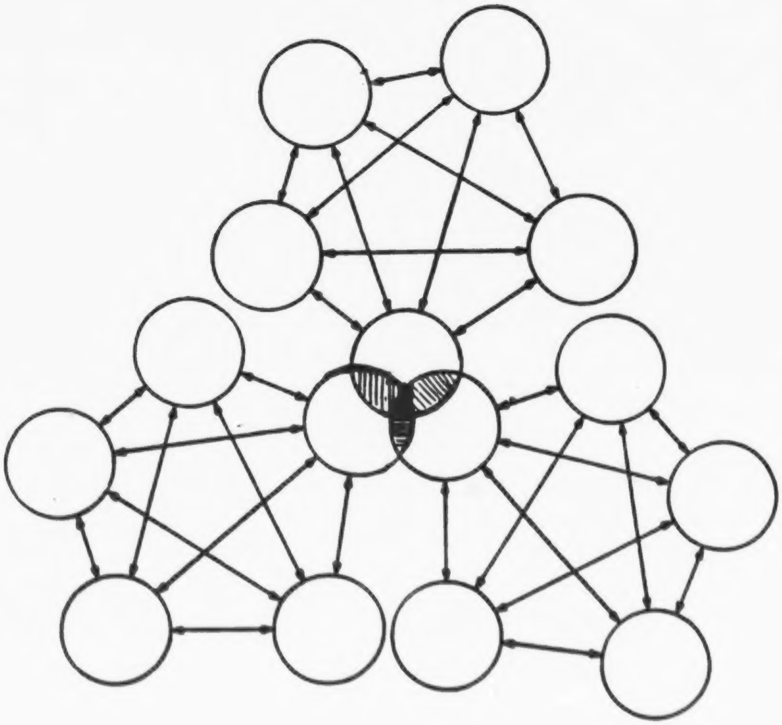
Question: **Can you illustrate what a typical system might look like?**

Answer: We present here an illustration that shows a number of systems in which a person could be a member. We also invite you to illustrate your own system on the next page.

TYPICAL SYSTEMS


PERSONAL SYSTEM
FAMILY SYSTEM
PROFESSIONAL SYSTEM
YOUR THERAPIST
YOUR RACQUETBALL PARTNER
YOUR DOCTOR
YOUR PEERS IN GRAD SCHOOL
YOU
YOUR SPOUSE
YOU
YOU
YOUR BOSS
YOUR CHILD'S TEACHER
YOUR COLLEAGUES
YOUR CHILD
YOUR MOTHER
YOUR SUBORDINATES
THE JANITOR ETC.

MY SYSTEMS



THE FAMILY AS A SYSTEM

Patricia A. Shank, Ph.D.

with

Susan M. Hansen

We hear much these days about systems. Turn on the T.V. or open a magazine and you're bound to hear an ad for an injector razor "system," a plant food "system," or a recessed filter "system." The advertising world has capitalized on the notion that by attaching the word "system" to a particular product, the consumer might be more inclined to believe in that product's superiority. What the consumer comes to learn, however, is that the advertised product "system" is no different that any other product that is comprised of various parts that, at least in theory, work together to accomplish some purpose.

Outside of the advertising world, the term "system" has been applied to phenomena whose essence we may not fully understand, but whose comprehension and functioning is dependent upon components that are interrelated in some way. For example, we may not understand the total essence of the solar system, the telephone system or the transit system, but we can comprehend that each system has its own unique components that interact in some way to form a whole.

Although systems thinking, as we shall describe it here, evolved from the world of computers, it has more recently been applied to understanding complex units such as the family. The applicability to an individual and his or her family of a theory that recognizes interrelatedness and interdependency is compelling. It becomes even more appealing when the issue of self and family empowerment is being addressed. Viewing the individual as a system and then incorporating that individual into larger and larger systems (such as the family system, the school system, the societal system) provides a framework through which the observer can focus on the interactions among system components rather than focusing solely on one particular person in isolation. The key notion here is that people are inextricably linked in interaction with each other. Interactions occur through the various modes of communication we use. In an interactive system (such as the family), the communications and behavior of one individual affect and are affected by all the other components or members of that system. Each system component (called a "subsystem") interconnects and influences the larger system.

Viewing the individual and the family from this perspective lends credence to the notions of empowerment and family cohesion. What empowers one will affect the potential for empowerment of others in the family. Those energies of interaction that enhance family cohesion, however, also have the potential of harming the emotional ties among family members if there is too much or too little. Centralizing most or all of the power in one family member can wreak havoc within the family system and certainly affect that family's healthy, growth-oriented functioning. The key is recognizing the central importance of each of the family's components and balancing the distribution of power and control among the components.

Because of each individual's and system's complexities, the process of individual and family growth is not a particularly easy or smooth one. Growing pains are inevitable and typically upsetting to the status quo of the system. Understanding what is happening from a less emotional, more systematic stance is far more productive than falling into a "head set" that needs to blame some*one* or some*thing*. Interactions occurring within a system are dynamic not static because systems themselves are: They are constantly in flux and changing because of the shared energies within.

We have included this section on systems concepts because of our belief in their application to the intent of the PARENT EMPOWERMENT PACKET (PEP); that is, to share ideas and resources that have the potential to empower. Understanding the family as a system enables a better understanding of the value and impact each member of the family has.

WHAT IS A SYSTEM?

A system is a set of interrelated, interdependent unit interacting for some purpose. Within complex systems, there are a number of subsystems or elements that provide those systems with their uniqueness. If those attributes were to change, the system itself would be different. The purpose of any systems is realized through the interaction of its elements. The processes in which family members engage, for example, will help (or hinder) that family's cohesiveness or its purpose of attaining optimal wellness.

All systems are part a larger systems or what are referred to as "suprasystems." The family, for example, is a subsystem of the extended family. The extended family affects and is affected by the singular family, and vice-versa. All systems operate in an environment. An environment is comprised of factors and conditions outside of the system that affect and are affected by the system. For example, the individual who is the smallest unit (subsystem) in a family, affects and is affected by the family environment. That environment is comprised of norms, values, traditions, beliefs, structures, etc. The family itself is a subsystem of the community in which it resides. The community also has its particular environmental characteristics such as neighbors (and their systems), schools (and their systems), and each of these have their economic conditions, norms, values, etc. These attributes influence and are influenced by the individual families making up that community.

DIFFERENT KINDS OF SYSTEMS

The type of system we have been discussing so far is called a "distributive" system; one that is comprised of smaller systems that are connected to and influence each other. It is interconnected and interdependent. Each component interacts with all other components. Control and power is evenly distributed and the system is in balance.

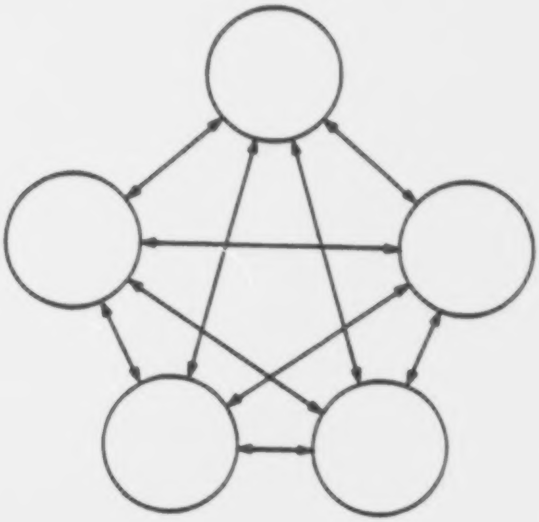


Figure 1: A distributive system

Figure 1 illustrates a distributive system. This particular configuration is significant because it can be used to represent a healthy family system.

A second type of system is referred to as a "totally integrated system." Figure 2 illustrates this type wherein the entire system is dependent upon some central component that serves as the "brains" of the operation -- the one part that controls the entire system.

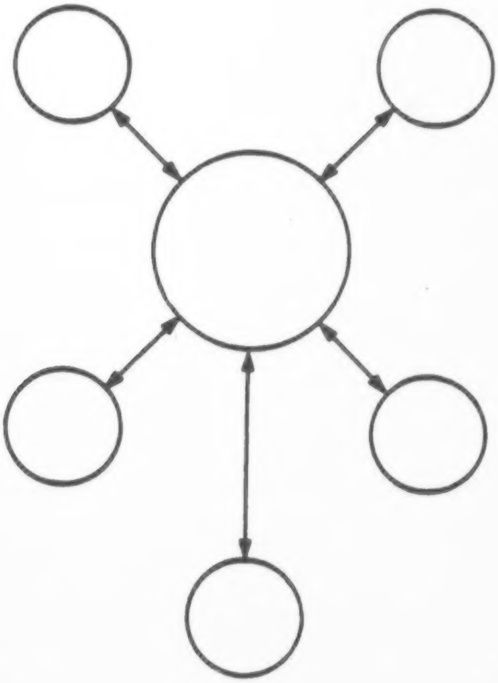


Figure 2: A totally integrated system

It can be readily seen that if the controlling component breaks down, the entire system will come to a halt. Furthermore, there is little or no meaningful interaction between and among the system's components -- the locus of control resides within the central component, in effect rendering the other system components powerless and dependent.

Applying this illustration to a family, the reader can see where one person is the central figure, that is, the one charged with meeting all the needs (the nurturer or the rescuer) of the entire system, or around whom the entire system attempts to function (the controller). The stress on the "nurturer" would be intolerable and within a short period of time, the entire family system would break down and become dysfunctional. The presence of a "controller" would be equally as devastating to the health of the system. The interrelatedness among family members is absent and all the power and control in the entire system is located within one member. Family cohesiveness and healthy functioning just isn´t found in the totally integrated system if it is allowed to continue -- the stress and pressure on the one component would be too great for the system to tolerate for too long.

This is a helpful analogy to which we shall return. At this point, let´s return to the individual, the smallest unit in the family system.

THE INDIVIDUAL

Understanding ourselves as a unique system comprised of interrelated subsystems is not difficult when we approach the task from a physiological perspective. We know something about the systems identified as cardiovascular, neuromuscular or gastrointestinal for example. These systems are comprised of elements that interact in some way to form the whole. They provide each other with information and feedback. In fact, the health of the individual (the larger system) is dependent on the information and feedback that is exchanged

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between and among each of the components or subsystems.

The individual also has her/his own self-perception and behaviors that are part of her/his wholeness and that influence the experience of self. The behavior that individual emits demonstrates answers to the questions of "Who am I?" and "What am I in relation to others?". Responses or feedback from others are interpreted by the individual through his or her own perception which can be self-enhancing as well as self-limiting. For example, if an individual consistently hears positive verbal and non-verbal messages about herself as a valued, capable person, she is more likely to incorporate those messages into her own self-perception. If an individual consistently hears messages about his lack of ability or worth, he will be inclined to believe that he is not very important or capable. Feedback is vital in systems thinking whether applied to understanding the individual member or the family as a whole system.

THE FAMILY

The family is more than just a collection of individuals each with their own physiological and psychological attributes and dynamics. It is the interaction of these individuals that provides something more than merely a sum of the parts. Each family has its own personality, its own inner life, and this life (environment) can be growth enhancing or inhibiting. Attempts at trying to understand an individual without some knowledge of the social context within which s/he functions seems narrow. It is for this reason, perhaps, why more and more professionals (educators, therapists, social workers, etc.) are incorporating a systems approach toward intervention. Understanding concepts integral to this approach may be helpful to the PEP reader who is trying to give some perspective to his or her unique situation and participation in various systems (family, friends, work environments, etc.). What follows is applicable to any system, not just family.

SUBSYSTEMS WITHIN THE FAMILY

Without going into the genesis of humankind, it might be helpful to begin the next illustration with two individuals who join together. Each individual brings her or his own genetic make-up, personality and behaviors, which as we have seen, were greatly influenced by their own family systems or families of origin. The two joined individuals separate themselves (i.e. differentiate) from the original systems and establish and commit themselves to their own new system (see Figure 3). Relationships with the extended family and friends become realigned to include the partner.

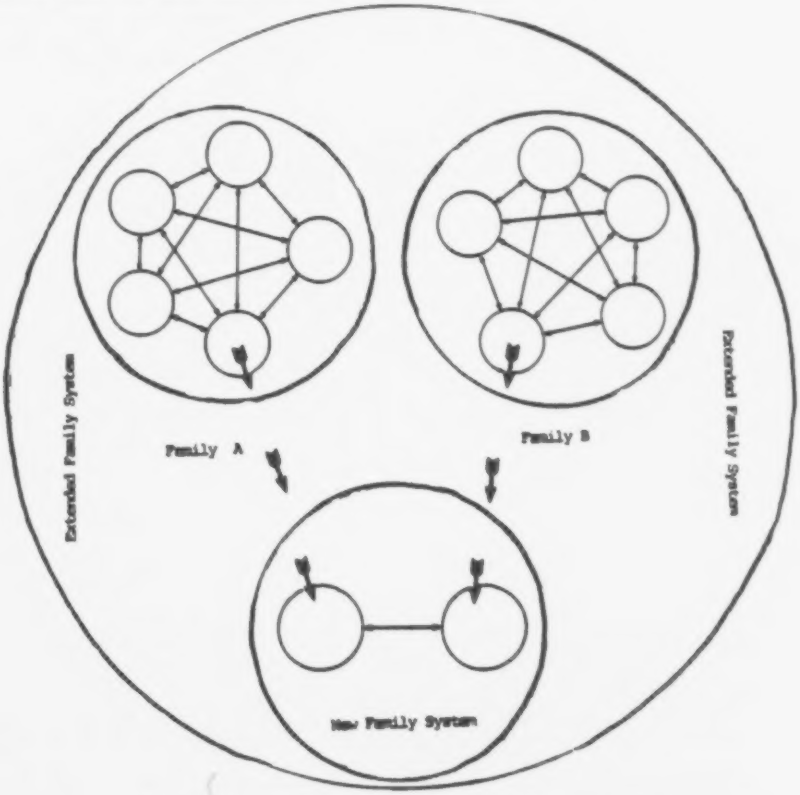

Figure 3: Establishment of a new system

This new system (like all systems) will have its own unique features. There will be boundaries or invisible lines which separate this system from all other systems. Hopefully, these boundaries will be flexible rather than rigid so that autonomy can be maintained without closing off connections to the outside world,

In addition to boundaries, there will be rules that the new system will establish. Rules refer to the implicit and explicit agreements the couple will make that will guide and influence their interactions. The expectations each partner has of the other are part of their rules.

The new system will eventually establish its own identity which is molded through interactions with each other and with other systems outside of their own. Roles will be established as will the system´s own norms and values. Value judgements about who should do what are often referred to as "role assignments." Role assignments can be overt or covert. For example, overt assignments may be fairly simple such as one individual being responsible for activities typically associated with men and the other individual responsible for those typically associated with women. Covert assignments are harder to discern. For example, one individual may be assigned the role of scapegoat while another may be assigned the role of peacemaker, or rescuer, or leader or victim.

Norms and values develop as a result of combining those that each person brings to the relationship usually after some negotiation. These norms and values will help define what is considered appropriate and inappropriate behaviors for the system.

When a child or a third person enters into this system, the structure becomes redefined. Structure refers to the family's overall subsystems, suprasystems, norms, values, roles and boundaries. Naturally, the more people entering the system, the more complex that system will be. The invisible lines between subsystems, as well as the subsystems' needs and expectation will all change. There will be a period of readjustment while the system attempts to re-establish equilibrium or harmony among all the components. Acknowledging that individuals grow and change provides a foundation for understanding that a system is something dynamic; that is, it is constantly making small readjustments to accommodate individuals' as well as its own growth and development.

SYSTEM COMPLEXITIES

It's worth repeating at this point that all systems function within an environment and that each subsystem is interconnected with and influences the larger system and all the other subsystems. The family interacts and exchanges information, that is, it communicates in a variety of ways in a variety of situations and it gives and responds to feedback.

A healthy environment is one that provides stability, yet remains flexible enough for each of its components to grow, develop and differentiate uniquely. A healthy family system is one that acknowledges change and supports individuality. It is an organized, unified whole that manages information, rules, consequences and expectations. It

> is affirmative in its attitudes and shows respect for the view of other family members. There is a firm parental coalition; however, they show openness as well as directness. Flexibility is demonstrated in the understanding of motivations and needs, and there is spontaneity in the interaction as members takes initiative in showing unique, individual qualities . . . Each family member is seen as

> capable of contributing and the family shares values which allow separation, loss and change to be handled (L´Abate, Ganahl & Hansen, 1986, p. 21).

The healthy family also recognizes and affords each individual with a "range" of functioning (Kaplan & Kaplan, 1978), i.e. a continuum view of individual behavior that says in essence, "We all have good days and not-so-good days." When behavior exceeds the range on either end, the family knows that something is not right with one of its members.

Family functioning can be understood from a perspective that looks at the cohesion or glue that holds the system together (or not as the case may be), the family´s adaptability in response to change and stress, and the family´s communication (Olsen, Russell & Sprenkle, 1979). Olson, Russell and Sprenkle (1983) define family cohesion as "the emotional bonding that family members have for one another." (p. 70) These authors state that family cohesion includes emotional bonding, boundaries, coalitions, time, space, friends, decision making, and interests and recreation. Cohesion and adaptability can be seen along a continuum from high to low. A family that is too involved or over-identified with each other is considered "enmeshed," while not enough cohesion indicates that a family is "disengaged," characterized by emotional, physical and/or intellectual isolation.

The authors define adaptability as "the ability of a marital or family system to change its power structure, role relationships and relationship rules in response to situational and developmental stress"(Olson, Russell & Sprenkle, 1983, p. 70). They see adaptability as being composed of the concepts of family power (which includes assertiveness, control and discipline), negotiation styles, role relationships and relationship rules. The adaptability continuum has four levels: On one end, adaptability is rigid, while on the opposite end, adaptability is chaotic. The two levels in between are called structured, which indicates low to moderate adaptability, and flexible, indicating moderate to high adaptability. Both of these levels indicate optimal family functioning while the extremes indicate pathology (Olson, Russell & Sprenkle, 1983). Communication is seen as facilitating cohesion and adaptability.

Because families are seen as dynamic, not static, cohesion and adaptability levels may vary situationally. However, the more stable the family unit is on these dimension, the more likely that family will be able to handle extreme stressors and crisis. This notion is particularly relevant to those family systems that include a member with a disability.

EFFECTS OF DISABILITY

The effects of disability on the intricate web of the family system unquestionably increases the complexity of that system, but does not necessarily lead to that family's dysfunction. It is important to remember that (a) all families differ, (b) all families have their own unique challenges and needs, and potential resources for adapting to and meeting these, and (c) all families are dynamic and therefore able to change those attributes that can be changed provided the desire and the ability to communicate that desire is present. Families evolve, change and transform sometimes subtly, sometimes radically. How well each family responds to its own dynamics is dependent upon its competency in handling the tasks with which it is confronted. Certain abilities must be present for the family to function competently.

FAMILY COMPETENCIES

The presence of problem-solving skills and open, effective communication are perhaps the most important abilities a family can possess for confronting and managing its day-to-day functioning and its particular challenges. Effective problem-solving requires a coordination of effort among all family members and an awareness on the part of each member of his or her contribution to the problem-solving process (Reiss, 1980). This implies the need for an environment that encourages autonomy or each member's taking responsibility for his or her own thoughts, feelings, and behavior.

Beavers (1982) has stated that in sharing tasks, optimally functioning families have the the capacity to "accept directions, organize themselves, develop input from each other, negotiate differences, and reach closure coherently and effectively." (p. 51) These abilities suggest that individual members have a strong sense of self-esteem, something that is established, maintained and nurtured by the overall system.

L'Abate (1976) views optimal family adjustment to challenges as occurring as a result of the family's ability to establish clear and appropriate priorities, boundaries and communication patterns (congruence between verbal and non-verbal messages). He identified appropriate priorities in the family as follows: self, marriage, children, parents and in-laws, work, leisure and friends. "Clear boundaries" pertain to the continuing process of differentiating the self from others. Congruence of communication patterns is defined by the degree of match between verbal and non-verbal messages.

Establishing boundaries may be one of the most essential tasks to confront when the family system includes an individual with disabilities. It is important to remember that each family subsystem has its own boundaries and that these boundaries should not be violated. Perhaps one of the more significant boundary violations occurs when the parent subsystem interferes with the sibling subsystem because they are overly concerned about the child with the disability. Norms or rules may develop that say that this child is special or privileged and that the other children (or the parents themselves) are less so. This may lead to the establishment of a "totally integrated system" referred to earlier wherein one member of the family controls (willingly or not) the behavior of and influences of the feedback heard by the other members of the family. [In another section of the PEP, the reader will be able to become more familiar with some of the particular difficulties confronted by brothers and sisters, so we won't focus on that here.]

Protection of parental and self boundaries is of paramount importance in any family but perhaps particularly important in families with special challenges. Individuals need privacy for self-reflection, self-development and self-revival. Couples need privacy to share intimacy, negotiate conflict, and to support each other in the difficult role of parenting. Too often, it becomes easy to lose sight of the emotional bonding between the couple because of daily family management tasks. It is essential for the parent as an individual and for parents as a couple to carve out space and time for themselves and for each other.

SUMMARY

This section of the PEP presented some concepts basic to a systems perspective of the family. A system was defined as a set of interrelated, interdependent units interacting for some purpose. A family can be regarded as a system that exists for the purpose of its own development and maintenance. It is comprised of subsystems that affect and are affected by each other and the larger system. The family's purpose is realized through the interaction of its components and through interaction with what was referred to as suprasystems. The environment both within and external to the family system provides the context within which norms, values, traditions, beliefs and structures are developed and maintained.

Two types of systems were presented: The distributive system and the totally integrated system. The former was used for illustrating a healthy family system wherein control and power are shared and connections and interdependencies are readily acknowledged.

Families, like all systems, have boundaries, structure and identity. These change as the system itself changes. The healthy family system maintains stability while remaining flexible to accommodate and adapt to the myriad changes. The key factors involved in adapting to the effects of disability are problem-solving skills and open communication.

Throughout the PEP, the notion of family systems will be referred to often. Worksheets have been provided in the manual that were designed to enhance family empowerment, and particularly to facilitate effective problem-solving skills and open communication.

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Sisters and Brothers

This section of the PEP describes some of the issues that may affect the sisters and brothers of individuals with disabilities and provides a list of resources particularly appropriate for siblings.

SISTERS AND BROTHERS

by Patricia A. Shank, Ph.D.

and

Susan M. Hansen

The family system is composed of a group of interrelated and interdependent parts that change and develop and grow through interaction. Recognizing that not all family systems are traditional in their make-up, we are defining the "family system" broadly; that is, the family system can be comprised of a variety of adult-child relationships. We use the term "parents" here in its natural context but also to refer to any adult assuming a parenting role in a particular system.

Each member of the family is equally important to the overall functioning of the system. The actions and growth of any one member will affect every other member of the system in some way. Changes in each member of the family system will require a functional reorganization of the whole system.

The family system concept is an important one in our attempts to understand some of the issues and dynamics challenging the sisters and brothers of the individual who is differently able. [See previous PEP section on, "The Family as a System."]

This section of the PEP will discuss some of the issues and provide some resources particularly relevant to siblings.

Family Subsystem Interactions and Boundaries

Within the family system, three types of interactions, each with their own power and dynamics, must be recognized. First, there is the the interaction that occurs between parents. It is within this family subsystem that most of the decision-making power resides (or should reside). Second, there is interaction between and among the children (the sibling subsystem). Third, there is the interactional system that involves the relationship between each parent and each child.

Each of these systems have their own boundaries just as the family itself does. These boundaries exist for the purpose of keeping members in as well as for keeping unwanted members out. Depending on the family, boundaries may be very loose, allowing nearly anyone inside or outside the family in, or they may be very rigid, neither allowing members out or outsiders in. Most families fall somewhere in between the two extremes.

Boundaries also exist within and around the subsystems of the family. The sibling subsystem has its role within the family and the parental subsystem has its role. The interaction between and among subsystems is paramount to the health of the entire system. This is particularly important in families where one of its members requires a great deal of attention because of the presence of a disability or chronic illness. Often problems develop when good-intentioned parents infiltrate the sibling subsystem to come to the aid of one of its members -- usually the child who is differently able. The results of such actions can be mild or severe, depending, of course, on the situation, the individuals within the situation and the action(s) taken.

Parents run the risk of alienating the sibling subsystem from themselves and each other by getting involved in issues that don´t really pertain to them or require their input. One of the most frequent mistakes parents make is to intrude into the sibling subsystem by unnecessarily coming to the aid of the child who is differently able. This overprotection can alienate the sisters and brothers and can prevent that child from ever becoming a real part of the sibling subsystem with all of its rights, responsibilities and,indeed, its conflicts. Learning to deal with conflict and its resolution is not only an important part of growing up, but also necessary to the emotional bonding between sister and brother. For a child to be truly integrated into each of the interactional systems within the family, s/he must be allowed to love, laugh, fight, express her-/himself, and live within that system as independently as possible.

Ideally, a family system functions best with both parents interacting in equal amounts with all of their children and with each other. Parents with a child who has a disability often, but not always, have difficulty accomplishing this because of the demands placed on the family by the disability´s characteristics. Certainly, parents cannot ignore these demands. The best they can do is to simply be aware that their actions do have an effect on every member of the family and that sisters and brothers have special and unique needs, also.

There are some issues and potential problems confronting sisters and brothers that parents can be aware of. Awareness is always the first step in problem solving. The remainder of this section, then, will be devoted to factors among siblings that are present in any family and some particularly important considerations for the family that has one or more members who are differently able.

Some Common Problems between Sisters and Brothers

Participating in a family system gives each member an opportunity to grow and to learn in a relatively safe environment. Children have a need to assert their own identities in order to develop and integrate their own uniqueness, their own specialness in the family, the peer group and the larger society. Their parents and their sisters and brothers can provide the necessary nurturing for this to occur. They, also, though, serve as the testing ground for the assertion of new behaviors and new demands that make their presence known, perhaps awkwardly, at different stages in the growth process. The results can often lead to family tension and bickering particularly among the siblings. Growth processes are not easy. They demand patience and, above all, understanding and a communication of that understanding.

Every child has the right and need to feel loved and special for each child is special. In some families that specialness is communicated with more ease than in others, for every family is indeed unique. In a family that has a member with disabilities, the challenge is even greater for establishing and nurturing communication that says unequivocally: We are all special; there is not one of us who is more important than another. Too often, the sister or brother who does not have a disability becomes the person who is handicapped by the disability of another. And, often the cause stems from inadequate communication [illegible] her/his own specialness.

Sisters and Brothers of the Differently Abled

There seems to be some common difficulties as well as common joys encountered by sisters and brothers of an individual who is differently able. We start this section with the difficulties first, but we'd like to point out that not all families experience the same things. Every family is different. How a brother or a sister will react and respond to his or her sibling will depend a lot on their position in the family, the onset of the disability, the severity of the disability or illness, and the relationship between parent and child. It may be helpful to some readers to become aware of some experiences of others even if just for the purpose of awareness.

Communication

Communication is the most important issue to be addressed in any family. It is perhaps even more essential that open, honest communication exists in the family with a difference.

While all brothers and sisters in any family system need to learn how to negotiate conflicts, friendships, fears and worries, the challenge is often greater for those living with a sibling who is different. Often they are confronted with conflicting feelings and impulses toward their sibling which may provoke fear, anger, frustration, jealousy, and resentfulness. If there is no outlet for communicating these feelings in a safe, non-threatening way, the ambivalence and confusion will often become compounded with the existing feeli[illegible]ilt and loneliness.

An[illegible]

All family members need to know that they have a right to their feelings. Obviously, some feelings are easier to express than others. Anger, for example, is one of the most difficult feelings to express in a constructive way and perhaps even more difficult for the sister or brother of an individual who is different. The angry feeling can stem from a number of things. Anger can result from feelings of being ignored, unappreciated, and overworked. It can result from the peer and societal injustices suffered by the sibling. It can stem from being left in the dark about the disability itself; that is, not being told exactly what the disability is, what it means in regard to the growth and development of the sibling or in regard to themselves and their future. The anger can be a result of embarrassment over the inappropriate or perhaps destructive behavior of the sibling who "doesn´t know any better."

Stuffing anger only makes it worse. Sisters, brother and parents need to learn and develop ways for openly and honestly confronting feelings of anger and for coping with its devastating effects. Talking it out helps, but sometimes, a physical outlet such as running or exercise will be needed first in order to help lessen the tendency toward explosiveness during the talking. If anger is recognized as the natural emotion it is and that it´s okay to feel it, families can help each other develop some positive ways for dealing with it.

Fear

It is not unusual for sisters and brother to be afraid of "catching" a disability or, if they are older than the sibling, of having caused it in the first place because of something they imagined they did or didn´t do. They may be afraid [illegible] being rejected by their friends or afraid that their sibling will be exposed to ridicule. As they get older, they often fear for the safety and welfare and future of their sibling while fearing that they may have to assume the caretaking responsibility. Passing on the illness and disability to their own offspring is also a very real fear felt by many brothers and sisters.

The best defense against fear is knowledge. There is no better way to dispel any type of fear. The more we know about whatever it is that is causing the fear, the better able we'll be to work through it.

Guilt

Guilt is another one of those complex feelings that is very difficult to cope with. The guilt can stem from the unexpressed feelings of anger and fear. It can also stem from sisters or brothers feelings of, "Why him and not me?" when they are confronted with the pain and difficulties encountered by their sibling, or conversely, from feelings of, "Better him than me."

Guilt is anger turned inside out and directed toward ourselves. The ways we develop for dealing with both fear and anger can also be helpful in dealing with guilt: acquiring knowledge and avenues for expression.

Pressures

The presence in the home of a person needing constant care and attention may cause real or sometimes imagined pressures for the sister or brother. She or he may attempt to take on too much responsibility for their sibling perhaps in the hope that the disability will go away, or that the parents will "love them, too." Oftentimes, some parents do expect the sister or brother to excel in order [illegible] compensate for the inabilities of the sibling. Or some expect that the sister or brother will become a "mini-parent" while still a child and a surrogate parent when they get older. This inappropriate role puts a tremendous burden on the sister or brother and may also give the sibling the message that he or she is unable to achieve independence and live "like normal people."

Although it may often seem as if there are few available resources for assisting parents with the care of their son or daughter who is differently able, overdependence on the siblings should be carefully watched for. Yet, a certain amount of dependence on the other children is normal and can actually help to make everyone feel that they are vital parts of the family system.

Sisters and brothers can be helpful teachers. There is tremendous power in the sibling subsystem. Sisters and brothers not only play together, grow together and learn together, but they also have inherent talents to teach each other. Social, language and play skills are first learned in the home and often through the interactions with sisters and brothers. Although this mentoring system is common in all families, it does not occur naturally in all families; it may need to be specifically taught and fostered.

Sisters and brothers need to be able to interact and to imitate certain behaviors in order to learn from each other. This implies also the need for attending behaviors; that is, the ability to attend to stimuli long enough to be able to process what is seen and heard. When one child has difficulty imitating or communicating or attending, the teaching-learning process is much more difficult. Sisters and brothers may need help in knowing how to "teach effectively." Several of the support groups and resources listed at the end of this chapter can provide the needed help. Classroom teachers, therapeutic recreators and others can also be tremendously helpful to the entire family in their effort to be effective helpers.

Probably the best way to avoid overdependence and the "mini-parent" syndrome is to establish a clear and realistic outline of sibling responsibilities and to keep and maintain open lines of communication among all family members.

What About the Joys?

In many families the joys associated with living with a sibling who is differently able far outweigh the difficulties. The special challenges often bring with them an extra-special sense of accomplishment. Little things take on a whole new perspective and don't seem so little after all. Sharing the pride in the sibling's accomplishments is one of the greatest experiences a brother or sister can feel.

Living with someone who is different often enables the brothers and sisters to become more understanding of the differences in people in general. Differences can be celebrated rather than shunned. This openness to others will enhance their ability to develop a rich and varied network of friends and acquaintances. Through the experience of living with a brother or sister with a disability, we come to learn that people aren't so different after all. We're much the same in many ways.

Sisters and brothers also learn a great deal from their differently-abled sibling. Because each member of the family is unique with his or her own special qualities, we all experience the giving and sharing that occurs naturally in families. And some of the greatest giving, often in the form of an unqu[illegible] comes from the individual with the difference.

Strat[illegible]

We'll end this section with some suggestions for parents adapted from Powell and Ogle (1985) for working toward effective communication between parents and siblings, for communication is the indeed the key in establishing a healthy, functional family system. We have added some of our own suggestions for coping and follow these with a variety of resources particularly helpful to sisters and brothers.

1. Actively listen to the siblings. Set aside some time regularly to talk. Your undivided attention is need if you are to be an effective listener so pick a time and a spot where distractions will be few. In order to make sure you really have heard what the child is trying to say, and so the child will know s/he has communicated clearly, rephrase what has been said until the child agrees with the content.

2. Take your time. Be patient as your child devises a personal way to ask painful, embarrassing or overwhelming questions. Sometimes sharing some of your own feelings will encourage the child to begin sharing her/his.

3. Serve as a model. Children are very good at learning by example. When they observe parents and professionals openly asking questions and seeking information, they will quickly learn that this is healthy and valued behavior.

4. Be knowledgeable. Parents are the primary source of information for siblings, the child with the disability and also for the extended family. The more you know about situations, the more able you'll be to make clear, informed choi[illegible] children will learn what you teach them.

5. [illegible] and sincere. There will be many times when you just don't know the a[illegible] A simple "I don't know" will suffice on these occasions especially when it is followed by a "But let's see if we can find out." If the answer to a question is one that will cause discomfort, take your time. Once you start "stretching the truth," you jeopardize the open communication between you and the child. If you need more information in order to answer a difficult question, you both might want to take a trip to a library or to talk with

someone who can help both of you.

6. Provide understandable answers. Sometimes it is difficult to understand what type of answer a child is looking for. Be aware that children of different ages will require different types of answers. For example, the four-year old will require a less complicated answer than the twelve year old. Questions such as, "Do you understand?" or "Does that make sense to you?" may help you decide to expand or limit an answer. Watch for the non-verbal communication also. It may be a lot more revealing than what is being said verbally.

7. Have an open attitude. As difficult as it might be, maintaining an open, caring attitude [illegible] be the [illegible] relationship. We may not always [illegible] children need to ask or say. [illegible] themselves and feel what [illegible] already been asked [illegible] might seem insignificant [illegible] persistent asking [illegible] notice me." And [illegible] If they are [illegible] significant and [illegible]

8. [illegible] about the [illegible] Concentrating on either [illegible] aspects [illegible] isn't fair nor is [illegible] or dangerous [illegible] fine" when it isn't [illegible] will be o.k." [illegible] as misleading as [illegible] never be any [illegible] don't know that. A healthy balance of hope, optimism and reality should serve the family well.

9. Capitalize on non-verbal communication. Some of the strongest forms of communication take place through non-verbal means such as facial expressions, body movements, and gestures. These can communicate many feelings. For example, where a brother or sister sits in relation to his/her sibling or how he/she looks at the sibling when addressed can provide much information about their feelings toward that person. Parents also need to be aware of the non-verbal messages they give. Children know intuitively when issues are being avoided, misinformation is being given or if the parent is having a hard time coping just as parents know the same about their children. Actions do indeed speak louder than words.

10. Openly deal with feelings. One of the most [illegible] things a parent can do is to encourage their children to explore [illegible]. Anger, fear, sadness and [illegible] are real feelings. Indi[illegible] and needs are also very real and children have a right to [illegible] range of feelings and emotions. Children need to know [illegible] selfish or wrong or bad for feeling them and that they [illegible] part of the growing-up [illegible] to learn that [illegible] their feelings [illegible] of ways of deal[illegible]. [illegible] of the most [illegible] with another per[illegible]

[illegible] Strategies

1. [illegible] of resources specifically [illegible]. There are a [illegible] available for sisters [illegible] journals, [illegible] are helpful in pro[illegible] about disabilities and about other families experiences in [illegible]. There are a number of groups for sisters and brothers and aside from the excellent support

they offer, these groups often sponsor workshops and other programs of interest. Many hospitals and schools also offer informative seminars and workshops that address issues concerning disability. Though certainly not for every sister or brother, counseling is yet another option that can provide advice, information, encouragement and above all, someone to objectively listen and care. Counseling can provide an arena in which to practice basic communication skills, evaluate needs, values, and feelings. It can also provide education in skill and attitude evaluation and restructuring.

2. Use resources available to the entire family. If respite care is available, use it. It can be a god-send for re-establishing the family bonds that that are so often tested by the effects of a disability. Home-health care is another option available in some communities as are special transportation, different types of financial assistance, advocacy services, social work support, recreation programs for the family, weekend family retreats, parent support groups, etc. Identify your family needs honestly then assertively go after the services and support you need letting go of any "shoulds" or "oughts" you might be holding on to.

Resources

[illegible] of *Sisters and Brothers* offer the reader a variety of re[illegible]ly relevant to siblings.

RESOURCES FOR SIBLINGS OF INDIVIDUALS WITH DISABILITIES

NOTE: Several of the resources listed below are also referenced in other sections of the PARENT EMPOWERMENT PACKET. This is by no means a complete listing of all resources available; however, the individuals compiling the resources felt that these represent a good mix of what is available. The reader is encouraged to contact the organizations and associations listed for more extensive information than that provided here.

ORGANIZATIONS

ASSOCIATION FOR THE CARE OF CHILDREN'S HEALTH (ACCH)

3615 Wisconsis Avenue, N.W.
Washington, D.C. 20016
(202) 244-1801

ACCH seeks to foster and promote the health and well-being of children and their families in health care settings. It serves as a resource for persons interested in the care of children with disabilities or who are chronically ill. ACCH publishes a quarterly journal, a bi-monthly newsletter and a number of bibliographies on different topics.

ASSOCIATION FOR CHILDREN AND ADULTS WITH LEARNING DISABILITIES (ACLD)

4156 Library Road
Pittsburg, PA 15234
(412) 341-1515

ACLD is an organization for professionals, adults with learning disabilities and their families. ACLD provides information about learning disabilities and advoca[illegible] and rehabilitative legislation affecting persons with learni[illegible]

THE CA[illegible] FOUNDATION

2025 Eye [illegible], N.W.
Suite 1011
Washington, D.C. 20006
(202) 659-5136

The Candlelighters Foundation is international in scope and consists of groups of parents who have or who had children with cancer. The Foundation distributes a variety of bibliographies pertaining to books and materials on cancer and dying for children at various age levels. The Candlelighters also sponsors conferences and workshops for families, publishes a quarterly newsletter for parents and a newsletter for teens, and serves as a clearinghouse on state and federal programs.

THE EXCEPTIONAL PARENT

605 Commonwealth Avenue
Boston, Massachusetts 02215
(617) 536-8961

The Exceptional Parent magazine provides practical information to siblings, parents, educators and other professionals involved with children and young adults with disabilities.

LET'S PLAY TO GROW (LPTG)

Kennedy Foundation
1701 K Street, N.W., Suite 205
Washington, D.C. 20006
(202) 331-1731

This program is dedicated to bringing information about and practical guidance for implementing play experiences into the lives of children with disabilities, their families and friends. The program has an international network of activity clubs and provides a kit of specially designed play guides. Parents and siblings can use the materials within the family or through and with other family groups.

LITTLE PEOPLE OF AMERICA (LPA)

Box 633
San Bruno, California 94066
(415) 589-0695

LPA was established as a nationwide organization for little people (or individuals who are dwarfs) for the purpose of fellowship and interchange of ideas, solutions to the problems of little persons, and for moral support. A special membership [illegible] provides opportunities for the exchange of information and offers [illegible] to parents and siblings of little persons. The organization publishes a newsletter and distributes printed materials on equipment and aids, [illegible] vocational adjustment.

NATIONAL EASTER SEALS SOCIETY

2023 West Ogden Avenue
Chicago, Illinois 60612
(312) 243-8400
(312) 243-8880 (TDD)

The society provides direct rehabilitation services to persons with disabilities and published a variety of books, pamphlets, and reprints for professionals, families, and persons with disabilities.

NATIONAL HEAD INJURY FOUNDATION

280 Singletary Lane
Framingham, Massachusetts
(617) 879-7473

The foundation, established by families of persons with head injuries and professionals with an interest in this condition, assists persons with head injuries and their families in seeking out needed resources and services. The foundation facilitates the formation of family support groups which exist in many locations throughout the country.

NATIONAL INFORMATION CENTER FOR HANDICAPPED CHILDREN AND YOUTH

1555 Wilson Boulevard, Suite 600
Rosslyn, Virginia 22209
(703) 522-0870

The Information Center is sponsored by the U.S. Department of Education. It collects and shares information and ideas that are helpful to persons with disabilities and their significant others. In addition, the Center answers questions, assists people in networking with each other and facilitates the exchange of information.

SIBLING INFORMATION NETWORK

The University of Connecticut
School of Education
Box U-64, Room 227
249 Glenbrook Road
Storrs, Connecticut [illegible]
(203) [illegible]

The Sibling [illegible] presently has over 1000 members from all regions of the [illegible] publishes a quarterly newsletter in addition [illegible] information for and about siblings of persons with [illegible] issues related to families of persons with disab[illegible]

SIBLING[illegible] CHANGE

Room 808
823 United Nations Plaza
New York, New York 10017
(212) 420-0776

This new division of Special Citizens Futures, Unlimited, Inc., was designed to unite siblings of individuals with disabilities for the purpose of advocacy, dissemination of information, provision of conferences and workshops for and about siblings and families, and to promote public awareness of the needs of people with disabilities and their families. Currently, the group is based in New York State but they plan to establish units throughout the United States.

SIBLINGS HELPING PERSONS WITH AUTISM THROUGH RESOURCES AND ENERGY (SHARE)

c/o National Society for Children and Adults with Autism (NSAC)
Suite 1017
1234 Massachusetts Avenue, N.W.
Washington, D.C. 20005-4599
(202) 783-0125

SHARE was formed as a committee in 1981 to utilize the talents and perspectives of siblings to serve the well-being of individuals with autism. A sibling-oriented column appears in the NSAC Advocate, the parent association's bi-monthly newsletter.

SIBLINGS UNDERSTANDING NEEDS (SUN)

Department of Pediatrics C-19
University of Texas Medical Branch
Galveston, Texas 77550

Siblings Understanding Needs publishes a [illegible] which is written by children and teenagers [illegible] disabilities or who are [illegible]

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Social Skills

This section of PEP addresses the issue of social skills from a parent's perspective and offers some sound advice for teaching these skills. The author has also included some suggestions pertaining to identifying support networks.

SOCIAL GROWTH IN CHILDREN WITH DISABILITIES:
AN OPEN LETTER FROM PARENT TO PARENT

by Susan Sternfeld

Many children with handicaps experience significant problems in growing socially. In and out of the school classroom, in and out of the family -- the myriad of events both problematic and non-problematic, which occur in daily living require the growing child to observe and react on his/her own behalf. From sharing toys, to making conversation, from feeling emotions to sustaining a sexual relationship, from helping in the house to holding down a job, from riding on a 'big wheel' to taking the 'T,' from joining in a family outing to initiating one's own leisure, from being kept safe by parents to recognizing and responding to danger, from playing with a friend to making and keeping friends--the child's social growth is continually noticeable to parents, siblings, friends, neighbors and teachers. It is even more noteworthy than academic achievement, for the ability to navigate the social world of family and friends and peers is the measuring stick of success as a social being. One's academic achievements or limitations 'take the back seat' when away from the classroom desk, and one's social achievements or limitations then 'climb into the front seat.' I don't mean to minimize cognitive learning in the realm of the '3R's,' nor do I intend to separate social learning from cognitive learning because the two are equal companions in helping a child grow and develop to his or her fullest capacity, but this essay's aim is perhaps to overstate the role and importance of social skill development in the lives of children with handicaps in hopes of driving home the message that we all--parents, teachers, neighbors, family and peers--have a full-time, 24-hour a day opportunity to teach our children how to navigate the world of social living.

The ideas presented here have been developed over the past 13 years as our family has lived with our son and helped him to grow into a responsive social person. We have found through a discussion group with five other families whose children have similar cognitive deficits that our problems and joys are not unique. For nearly five years of group meetings the primary topics of discussion have been around issues of social awareness and development. For example:

-How do you handle being called a 'retard?'

-Is getting an after-school job possible?

-How can you improve someone's table manners?

-Can she answer the telephone and take a message?

-Does my child get invited to play or to birthday parties?

-Can he choose appropriate clothes for school?

-Can she learn how to ride a bike so as to play with neighborhood children?

-Does he recognize and respond to danger?

-Will she take turns in a game with rules?

-Is he taken advantage of by other children?

-Can she stand in line without bumping others?

-Does he remember to bring his lunch box to the cafeteria?

-Can she control anger or upset feelings?

-Can he pay for things in a store or cafeteria?

-Does she talk to strangers?

-Can he carry on a conversation with classmates?

-Are there feelings of inadequacy when younger siblings surpass you in everything?

As I read over the above list I am again struck by the fact that every item on it (with the exception of the last) is a question we could ask of any child no matter how normal their development, the difference comes in several ways: at what age are these issues arising, how easily will the child learn to do it, how much outside support will be needed to maintain the level of competence, and at what point do you let go because you have confidence in the child's ability to act independently? The tension and problems arise not because of the social skill itself but because our children don't seem able to learn it on their own. We have found that they need to be taught and re-taught simple tasks that other children learn seemingly by osmosis. For example, because we don't expect to have to teach a 12 year old child how to answer the telephone, we as parents are not used to looking at all the tiny skills that the child must have acquired before he or she can successfully complete such a seemingly easy task as answering the phone. For example, the child must know that it is the phone making the noise, that by grabbing and lifting the receiver the noise will stop, that by placing the listening end to his ear he will hear a person's voice, that the person speaking wants to talk to someone, that the child must say something so the caller knows he is there, the caller will ask to speak to someone ("May I talk to your Mummy please?"), the child must say, "I'll get her," the child must go and tell Mummy that she has a phone call. What happens with most children is that they will observe the phoning procedure done in their own family, and then will play act with toy phones as small children, then one day they will try it on their own. They have observed and absorbed the pieces needed to complete the phoning sequence, they have 'imagined' it in their play activities, and then when ready have tried it for real. There appears to be an inner drive capable of observing and organizing the behavioral information. With mentally handicapped children teaching must often be substituted for the inner drive. But how can this be done?

I believe that by using the four easy steps which are outlined below, anyone in a home, school, playground, or camp setting can quickly and simply grasp the social aspects of a problem situation and bring them under control, first conceptually, and then in a practical teaching approach. This does not mean that the problem will be solved overnight, but it does mean that you as the parent or teacher have a tool which will begin to give you a sense of mastery over the seemingly uncontrollable vagaries of social development in the child whose overall development path is out of step with so-called normal development.

The four steps are:

1. ANALYZE -- Breaking the problem situation into the tiniest sequence of skills possible.

2. TEACH -- Creating the 'inner drive' or series of skills needed to complete the task through a variety of teaching methods.

3. GENERALIZE -- "Taking the show on the road" and practicing the learned skills in many different locations.

4. EVALUATE -- Observing the 'empowered' child performing the task on his/her own with no coaching, or observing the child still having problems which necessitate a return to Step #1.

Let's now turn to some examples of these steps taking place in real-life situations. The examples are all drawn from either our own or our friends family experiences and represent different ages, stages of development and settings. There is no right or wrong way to solve a problem, but by using the four-step process outlined above you can develop a 'social skills eye'--a new way of looking at social problems in your child's life.

STEP #1 -- ANALYZE THE ACTIVITY

In each social situation, analysis must occur on four levels: (1) the physical tasks involved in the activity, (2) the conversational or interpersonal skills which are part of the activity, (3) the emotional capacity and responses of the individual, and (4) the cognitive skills required by the activity. The following incident occured in an after-school day care program: Brian (aged 9, grade 2) was playing floor hockey with one other boy (age 7, grade 2). Brian and Mark were passing the puck back and forth to each other and taking turns shooting it at the goal which was marked by two chairs. Soon they were joined by two other boys who also wanted to play, so two teams were decided on and two goals were set up at opposite ends of the gym. The boys began shooting and running and fighting for the puck up and down the gym. Brian threw his stick down and stomped off to a corner crying and refusing to play. Now the teams were uneven and the boys were surprised and angry with Brian for spoiling their game. At this point a teacher came and suggested that he himself would become the goalie and they could all take turns shooting at him. Everyone liked this idea and Brian was soon back in the thick of the action.

This incident shows the importance of considering the often confusing details and the many skills needed to play a team game successfully. Brian knew how to hold the stick, aim and shoot the puck, pass it to one player and receive a pass--he had learned most of the physical tasks required for this activity. He could perform all of these well when there was a slow pace to the game and only one other player. However, he fell apart when others pressured him to move quickly and compete against one another. The added social interaction of two people on an opposing team created an interpersonal tension he could not deal with positively. He did not know how to say, "I'm upset because the game is moving too fast and I'm confused by all the rushing around." When the rules of the game were changed to everyone taking shots at one goalie, Brian was again able to play with the others.

What then does Brian need to learn in order to play a competitive game of hockey? On the physical level he has the puck and stick handling skills, but now he must learn to take a puck away from someone else and once he has it to try and defend his puck from others taking it. On the interpersonal level he must learn to play with another player on his team in a sort of 'keep away' game. He must learn to anticipate when someone is coming who will try to grab the puck. And he must keep track of people on his team and communicate with them as to what he is doing -- e.g. "Shoot it to me, I'm free," or "Mark, this is yours." He could alternatively be helped to think of and suggest ways for playing a game that are easier for him to handle, e.g. "Let's pretend we're all on the same team and shoot at one goal. That's easier for me to do. Is that OK with you guys?" On the emotional level he needs to be helped to find an alternative way to express his frustration through words (as outlined in the next section) and increased skill and practice. On the cognitive level he needs to learn the concept of competition and its give and take nature. Thus it is crucial to look at all four aspects -- physical, interpersonl, cognitive and emotional -- of an activity for together they compose the whole. It is a process of breaking the activity down so it can then be rebuilt via the next step.

STEP #2 -- TEACH THE "INNER DRIVE"

Continuing with the floor hockey example, what approach can be used to help the child play competitively? One solution has been suggested already, that is change the rules and all shoot at one goal. However, sometimes this won't happen so Brian can be helped to function in a more competitive game in a variety of ways. In a one on one teaching situation he can get practice in taking the puck away from another player. He can be taught how to maneuver his stick around the other's stick and knock the puck free. When he feels capable of doing this he can be taught how to prevent someone from stealing the puck from him. Finally, he can be slowly taught that sometimes he will lose the puck and that when this happens he needs to try to steal it back. Thus, through these physical skills he is learning the concept of competition. One on one practice would be the best way to start, and since this is a sport, he can be told he is receiving special help from his 'private' coach. Lots of positive praise and encouragement will sustain his interest and help control the feelings of frustration that will arise around failures to get or keep the puck. Conversation can occur in the form of: "Brian, tell me what you're trying to do." "I'm trying to take the puck away from you." Or, "Here he comes, I'm going to block him." Or, "Yikes, he got the puck, now it's my turn to take it from him." Thus, through the use of verbal dialogue he can begin to bring self-control to the emotional aspects involved in competition.

In another example, Joel (age 17, grade 10) had been working first as a bagger in a supermarket, then as a bottle recycling cashier. He was then promoted to the flower shop where he had to operate a cash register, wrap plants and flowers, and talk with a lot of customers. He quit in total frustration and despair because the job became too confusing. His physical prowess on the cash register was very limited and when combined with a variety of other tasks which were also difficult, he collapsed in failure. Again, the teaching component necessary for the successful transition to a new job would have included: practice on the cash resister both giving and receiving money when no customers were present, or as part of a school vocational program; handling and wrapping flowers and plants in a training program; and learning how to talk with impatient customers by saying "I'll be with you as soon as I have helped this person." "I'm new on the job so I'm a little slow, please be patient with me." "I'm sorry, I don't know the answer to that question, I"ll have to ask my supervisor." In this way the necessary skills would have become internalized and he could have begun to feel capable of handling the various parts of the job without getting confused and frustrated.

STEP #3 -- GENERALIZE TO OTHER SETTINGS

Before any skill can be considered a permanent part of someone's repertoire, it must be useable in a variety of appropriate locations. For example, when teaching a child how to answer a phone or initiate a call, practicing on a single phone at home will build up the necessary confidence in knowing how to work the machinery and say the correct words. Then one must 'take the show on the road' and have the child practice using phones in different locations and with different dials. Possibilities include: wall phones, different desk phones, phones in restaurants, public phone booths, a friend's house, or the school office. Later on learning to take or leave a message on an answering machine can be taught using the same process of analyzing, teaching and generalizing.

In a different situation, a particularly sensitive APE teacher had been teaching teamwork to a group of boys (age 12, grade 5) using the game of basketball. She had worked for several months on the rules of dribbling and passing, and the skills of throwing the ball just ahead of the person and how you must keep track of where your teammates are at all times. One Spring afternoon she was delighted to observe three of these boys playing with three older boys after school on the playground court. They were holding their own in the game which had been organized with no adult supervision. The boys were clearly demonstrating the success of her teaching by applying the skills and confidence she had taught them to a free play setting. This is a truly generalized skill.

STEP #4 -- EVALUATE PROGRESS

At the same time, these boys were also demonstrating that they had become empowered in this activity to the point of being able to risk testing their new-found skills against fresh competition. Other signs of empowerment and independence can be observed when a child says, "Can I play with you?" as a way of joining a group and is allowed to join; or the child contributes an appropriate comment into a general mealtime conversation, or notices that someone is struggling with a grocery bag and offers to help, or notices that there is no room for two shopping carts to pass and lets the other person through first, or congratulates a teammate on a good shot in a basketball game, or compliments someone on how nice they look. On the other hand, sometimes the child will try a new skill but be unsuccessful, at which point you must return to Step #1 and analyze what pieces are still causing problems. For example, in the hockey game, the physical skills were acquired but the competitive nature of the interactions was still in need of teaching.

In another example, Danny (age 8, grade 2) and several other children were walking across the playing field. Danny came running up to me and said, "Amber (age 12, grade 5)and Brian (age 9, grade 2) are being mean to me." I asked what they had done. He replied, "They won't let me walk with them. I said, "Did you ask them if you could join them?" He replied, "Yes."

S: "Show me what you said to them."

Danny ran up to them and lightly touched Amber on the arm and said, "Hi." Amber and Brian were deep in conversation with each other and barely noticed Danny's touch. He rushed back and said:

D: "See, I told you they're mean.

S: I think Amber didn't feel you touch her or hear you speak to her.

Danny repeated his attempt and touched harder and spoke louder, still no response.

S: "I think they are in the middle of a conversation, why don't you try walking beside them until they are finished, and then you can join in."

Danny did this for a short time and then found someone else to walk with. It appears that Danny knows what to say and do as a first attempt to join a group, but needs to develop alternative actions when this doesn't work the first time. Practicing in a play-acting situation would give him the opportunity to suggest different things he could try such as walking and waiting his turn; finding someone else; and interrupting in a polite way. At the same time, the others in the play-acting would be learning that they can be aware of others who want to join their group and make room to include them. Helping children learn to 'read' the cues in a social situation and react to them in a constructive way is the ultimate aim of any social awareness training--whether it is done formally in a school-based instruction program or informally around the family supper table.

It is hard to imagine how many individual skills are involved in social situations so I have included in Appendix #1 a list of common social skills. This is by no means an exhaustive list but I hope it will help when you look at what is a problem situation for your child. For example, if you notice your child barges into the middle of a board game making everyone cross with him/her, you know that the skill of "Joining in" needs to be taught. This might be done through immediate verbal coaching, or play-acting the situation at another time. It may also transpire that the child then needs help with the next skill "Playing a game," and so on. At this point, using the four-step process of analyzing, teaching, generalizing and evaluating will, I hope, provide you with a practical method for understanding and encouraging social development in your child.

SOCIAL GROWTH LOOKED AT DEVELOPMENTALLY

A brief look at the nature of social growth from infancy to young adulthood will serve to show the different social skills needed at each stage and how these are part of a progression. Play is the vehicle by which a child employs his or her social skills for the purpose of making friends. Through play the child practices these skills and receives feedback as to their success or not from others sharing his play activity. For the *infant and toddler,* play and personal interactions are usually done with parents, older siblings, and other people close to the family. Learning to explore and minipulate his small intimate world using all his senses is the baby's first outreach effort. *Early childhood* usually is marked by an increase in social contacts outside the family and the first emergence of peer play asnd friendship formation on a very simple level. That is, "A friend is someone I play with," or "He let me play with his truck, he's my friend now." In *middle childhood* there is an increasing focus on games and organized play in groups (often split into all boys and all girls) both formally and informally formed. Thus, interpersonal skills must include learning how to join groups and understanding and following the rules of whatever game has been started. Sometimes it is an imaginative game with its own rules, sometimes it is a familiar game of tag or kickball. Thus friendship is marked by being part of a group and sharing and planning the games together. By *adolescence* play and friendship-formation have begun to separate and although you may play a sport with many others, friendships depend on far more that just shared activities. Mutual interests, likes and dislikes, attitudes to people, and so on now form the basis for friendships which are viewed as long lasting. Also during this period of growth boys and girls become increasingly interested in each other and so the social skills involved in dating habits and sexual behavior become crucial at this time. *Young adulthood* marks the passage out of the home into the "real" world of job finding and keeping, independent living, and eventually marriage and starting a family. An ability to get along with other employees in a job, to do the job task well, to seek out living space, to plan one's own leisure and transportation, to initiate and sustain new friendships, to seek help when needed, to decide on marriage and child rearing--all involve using the many social skills that have been practiced over the years in play, family, and school settings. Social skills act as the connecting link between the individual and his or her social world at whatever age. They are what empower the individual to be his or her own best advocate, to interact with the people and services around him and to thus live a life filled with people who care.

This brief outline of social growth focused on normal development and thus one may question its relevance in this essay. However, in order to understand why our children are having trouble socially, it is crucial that we understand what social level they themselves are on in comparison to the social level of those with whom they are interacting. For if a ten year old is offering a truck as a means of joining a group of boys who are playing a kickball game, he will be jeered off the field. In this case, the ten year old might be better off playing with his truck with younger children and at the same time be taught the skills and rules necessary to join the kickball game another day.

Thus, a well-developed 'social skills eye' will include:

- understanding the child's social and cognitive stage of development;

- itemizing the specific skills needed for the activity;
- listing the child's present skills;
- understanding the interpersonal qualities in the situation;
- noting what emotions are aroused in the situation both for your child and for those with whom he/she is interacting;
- initiating the four-step process which is designed to be cyclical in nature - that is, "If at first you don't succeed, try, try again!" by returning to Step #1;
- and, perhaps most important and difficult of all, being able to separate your own feeling of pain from your child's so that you are able to embark on Step #1 and analyze the activity or social situation.

As you help your child develop his or her social skills, you are simultaneously creating a social network that will prevent the feelings of isolation which are often a factor in the lives of handicapped children and their families. Appendix #2 is called "Creating a Support Network" and is included to help you broaden your thinking as to who might be called upon as a resource for you and your family in moments of need. It suggests ways to create or enlarge your own support network so that the entire family has the social connections necessary for healthy growth and development.

Good luck, and I hope these thoughts will prove useful to your family.

APPENDIX # 1 - SOCIAL SKILLS LIST

Functioning in the classroom, home or other group setting

- Listening
- Asking for help
- Asking for permission
- Saying thank you
- Bringing material to class
- Following instructions
- Completing assignments
- Contributing to discussions
- Offering help to an adult
- Asking a question
- Working independently
- Ignoring distractions
- Making corrections
- Working in a group
- Participating in class
- Deciding on something to do
- Setting a goal
- Paying attention

Making friends

- Introducing yourself
- Beginning a conversation
- Ending a conversation
- Joining in
- Playing a game
- Showing sportsmanship
- Asking a favor
- Offering help
- Giving a compliment
- Accepting a compliment
- Sharing an activity
- Sharing
- Apologizing

Understanding feelings

- Knowing your feelings
- Expressing your feelings
- Recognizing another's feelings
- Showing understanding of another's feelings
- Expressing concern for another
- Dealing with being left out
- Dealing with your anger
- Dealing with another's anger
- Dealing with embarrassment
- Expressing affection
- Dealing with fear
- Rewarding yourself

Coping with conflict

- Using self-control
- Responding to name-calling and teasing
- Staying out of fights
- Avoiding trouble
- Handling criticism
- Negotiating
- Accepting authority
- Problem solving
- Reacting to failure
- Dealing with group pressure
- Telling the truth

from Nezer, H.W., Nezer, B.R., Siperstein, G.N. *Improving Children's Social Skills: Techniques for Teachers. (Teacher's Training Manual.)* The Center for the Study of Social Acceptance. University of Massachusetts/Boston, 1985.

APPENDIX # 2 - CREATING A SUPPORT NETWORK

Questions to ask yourself:

How do I state my need for support?
Who can I turn to for support?
How do I know I need support?
How long do I need it for?
What kind of support do I need? For me? For my child? Physical equipment? Emotional? Monetary?

Types of support utilized over the years:

general parenting training
peer support groups for self and child
medical
babysitting and respite care
equipment and supplies
education for self and child
informal support via phone calls, personal contact, reading material, etc.

Personal support plan:

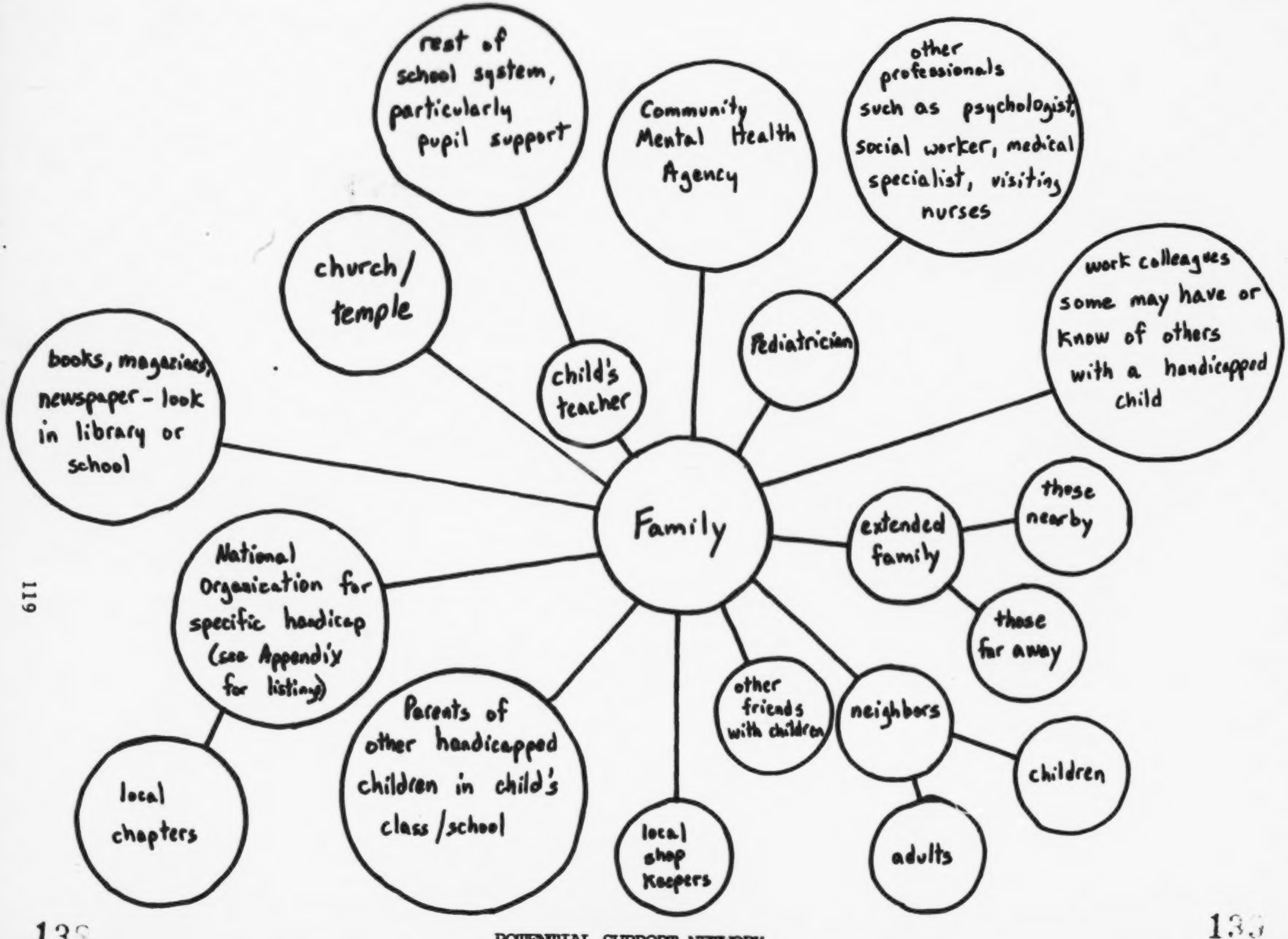
Look at the spider web network of possible supports in Figure 1 and circle those which you have used or are using now. Then circle with a different color those which you haven't used but might be able to use with a little effort. If there are still some remaining, circle those which you could use with a lot of effort with a third color. If there are any which you think would be impossible to utilize, decide what it is that makes them so and whether or not they are worth pursuing at another time.

Make your own support network web by filling in the names of family, friends, professionals, etc. in your life who have, or would be willing to help you and your family.

Don't forget the local shopkeeper who might be willing to help your child become an independent shopper.

Don't overlook a neighborhood teenager who can be enlisted to introduce your child to the neighborhood or school playground, or just to the local street games.

Based on ideas from: Slater, M.A., and Wikler, L. "Normalized Family Resources for Families with a Developmentally Disabled Child." Social Work. 31:5, pp. 385-390, 1986.


rest of school system, particularly pupil support
Community Mental Health Agency
other professionals such as psychologist, social worker, medical specialist, visiting nurses
church/temple
child's teacher
Pediatrician
work colleagues some may have or know of others with a handicapped child
books, magazines, newspaper - look in library or school
Family
extended family
those nearby
those far away
National Organization for specific handicap (see Appendix for listing)
local chapters
Parents of other handicapped children in child's class/school
local shop keepers
other friends with children
neighbors
children
adults

POTENTIAL SUPPORT NETWORK

SOCIAL SKILLS ANNOTATED BIBLIOGRAPHY

Compiled by Susan L. Sternfeld

Books for Background Information

Asher, S.R., and Gottman, S.M. The Development of Children's Friendships. Cambridge: University of Cambridge, 1981.

This is a collection of 12 articles dealing with a variety of the issues surrounding the study of how children form and maintain relationships with their peers. Part I, "Group Processes," focuses on the peer-group setting and its structure, while Part II, "Social-Cognitive Processes," focuses on the intrapsychic processes that relate to friendship formation.

Dickerson, M.U., Social Work Practice with the Mentally Retarded. New York: The Free Press, 1981.

This is a very sensitive guide to working with mentally retarded clients which is useful for anyone serving this population. Chapters 6 and 7 are particularly helpful in understanding the importance of viewing the retarded client as a person of integrity who is just as capable of growth and development as non-handicapped individuals. These two chapters focus on ways the practitioner can empower the client to assume personal responsibility for his or her own life, to the greatest extent possible.

Hersh, R.H., Paolitto, D.P., and Reimer, J. Promoting Moral Growth: From Piaget to Kohlberg. New York: Longman, 1979.

This book presents an introduction to Piaget's and Kohlberg's theories of the cognitive-developmental approach to moral education. That is, the child's ability to take into account the values of others in relation to his own values, and then act on these combined values, forms the basis of his moral judgement. The authors stress the relationship of cognitive development stages and socio-moral development stages.

Piaget, J. The Moral Judgment of the Child. New York: The Free Press, 1965..

This book was originally published in 1932, and grew out of research that Piaget was doing at the time. Apparently, he did not continue developing his ideas of how children acquire moral judgement, but the recent work of Kohlberg and others in the field of social perspective taking abiltiy is heavily rooted in Piaget's work.

Rubin, Z. Children's Friendships. Cambridge, Mass: Harvard Universtiy Press, 1980.

This is a highly readable book which will provide lay and professional alike with an interesting overview of how children form friendships at different ages.

Schloss, P.J. Social Development of Handicapped Children and Adolescents. Rockville, Md: An Aspen Publication, 1984.

This is a fine book for educators working with handicapped people and presents a review of the theoretical constructs on which social skill development is based as well as chapters on identification of social development deficits, classroom training approaches, teacher-student relationships, and program planning and evaluation.

Stocking, S.H., Arezzo, D., and Leavitt, S. Helping Kids Make Friends. Allen, Texas: Argus Communications, 1980.

This is a short, pamphlet-like book which presents in a clear and direct style many practical steps people working with young children can do to help them with friendship formation skills.

Books on Parenting Skills

Dinkmeyer, D., and McKay, G.D. Systematic Training for Effective Parenting. Circle Pines, Minn: American Guidance Service, Inc., 1976.

This is a group training program for parents who want to become more effective parents. The group leader(s) serve more as facilitators than as authorities and instructors on 'good' parenting. The major goals are applicable to all parent groups as they concern topics such as understanding behavior and misbehavior, building self-esteem, listening, exploring alternatives, using natural and logical consequences, and learning about yourself as a parent.

Ginot, H.G. Between Parent and Child. New York: Avon Books, 1965.

Illustrated dialogues and anecdotes support the many ideas for improving communication between parent and child so that a relationship of mutual responsibility, love and respect is firmly established. The basic ideas are true for all interpersonal communication and thus the book will be useful for anyone in the helping professions. Dr. Ginot has also written a book called Between Parent and Teenager which illustrates how the ideas can ease some of the problems usually associated with these years.

Newson, E., and Hipgrave, T. Getting Through to Your Handicapped Child. Cambridge: Cambridge University Press, 1982.

This book looks at the behaviors of the child and the behaviors of the parent in an attempt to help each to understand the other and thus to improve parent-child communication. The format is presented in such a way that it can be used in a workshop setting where parents and/or professionals are attempting to get a better understanding of how to reach the handicapped child with clear and direct messages he/she can truly understand.

Wolf, J.S. and Stephens, TJ. M. Effective Skills in Parent/Teacher Conferencing: The Parent's Perspective. NCEMMH, The Ohio State University, Columbus, Ohio, 1981.

This is a booklet designed to be used as a resource to help parents communicate with school personnel effectively. It discusses specific competencies such as breaking down barriers to communication, asking for information, expressing concerns and feelings, and developing strategies for follow-up.

Books on Play

Garvey, C. Play. Cambridge, Mass: Harvard University Press, 1977.

The author departs slightly from Piaget's approach to play by emphasizing the social nature of play from the very beginnings of infancy. Garvey classifies play into five groups based on the material or resources which are primarily involved.

The groups are: (1) play with motion and interaction; (2) play with objects; (3) play with language; (4) play with social materials; and (5) play with rules. She then traces each of these through their lines of development using examples from her own research and that of others.

Grasselli, R.N., and Hegner, P.A. *Playful Parenting.* New York: Putnam, 1981.

A wonderful array of activities, games and physical exercises that parents can use with their children from infancy to the fourth birthday. The book is divided into three sections: Diaper Play (6 weeks to 12 months), Toddler Play (13 months to 2 years), and Mini Play (25 months to 3 years). There are delightful drawings and photos of parents and children engaged in the activities, and clear descriptions of materials and directions for each exercise. Playful parenting has been taught by the authors in clinics and classes throughout California, and it has been licensed by the California State Regional Center for the Handicapped. However, it can also be used by parents on their own in formally designated play-times, or informally built into daily activities.

Gritchel, S. and Foster, L.. *Let's Talk About...s-e-x A Read and Discuss Guide for People 9-12 and Their Parents.* Fresno, Calif. Planned Parenthood, 1983.

This is a particularly good book on the topic because it is a mutual exploration for parents and young people. The section for parents answers some of the concerns and fears that many parents have when the word 'sex' is mentioned.

Pappas, M.G. *Prime Time for Families: Over 50 Activities, Games, and Exercises for Personal and Family Growth.* Minneapolis, Minn: Winston Press, 1980.

This fun-filled book is designed to help children and adults to look at their lives and values through a series of activities which are experienced as a family. The family thus learns to improve and enhance their communication, sharing, exploring, feeling, and caring in a safe and supportive way. The ground-rules for this family-experience are: (1) Each person has the right to act as activity leader; (2) Each person has the right to pass; (3) Each person has the right to a supportive growth atmosphere; (4) Each person has the right to confidentiality. This offers a unique way for a family to have fun together, to improve communication, to build individual and family self-esteem, and to get to know each other better.

Prutzman, P., Burger, M.L., Bodenhamer, G., and Stern, L. *The Friendly Classroom for a Small Planet: A Handbook on Creative Approaches to Living and Problem Solving for Children.* Wayne, NJ: Avery Publishing Group, Inc., 1978.

This facilitator's and/or teacher's guide is full of activities and suggestions which will build a sense of cooperation, community and mutual trust among groups of children. It is designed for use in schools, but is easily applied to other group settings. With some modification and sensitivity to the needs of the group, the ideas can be used with a wide variety of ages from children to adult.

Torbert, M. *Follow Me: A Handbook of Movement Activities for Children.* Englewood Cliffs, N.J.:Prentice-Hall, 1980.

This book includes over 100 movement activities which are presented and analyzed in ways that increase our understanding of how the activity can meet specific needs in the areas of: perceptual motor development, attention span and concentration, listening skills, release of tension and excessive energy, self-control, development of thinking processes, reinforcement of learned information, social growth, physical abilities, annd physical fitness. These activities can be done in many settings--school, community, home--wherever groups of children and/or adults are together.

Curriculum Materials

Adolescent Issues Project. Judge Baker Guidance Center, 295 Longwood Ave., Boston, Mass. 02115.

The five programs developed by this group of educators and researchers are firmly based in the problem-solving theories of social skill development. The units are: (1) Decisions About Drug Use, (2) Adolescent Development and Sexuality, (3) Decisions About Work, (4) Juvenile Law, (5) People and the Governent. The materials have been successfully used (with adaptions where warranted) with special and regular education students from grades 4-12. The reading level is at approximately the fifth grade. The unit on Sexuality deals not only with the biological changes of adolescence, but also with the social changes related to sexual development. In fact, the primary intent is to help adolescents and those working with them to understand the complex nature of interpersonal relationships and how problem-solving methods will help in this learning process.

Agency for Instructional Television. Box A, Bloomington, Indiana (47402).

The following video programs are those suggested by M.J. Elias and C.A. Maher in their 1983 article on social and affective development for children:

"Ripples"and "All About You"(K-2) "Learning about one's body: learning about the world around us; understanding oneself and relationships with others; developing personal initiative.

"Inside/Out"(3-6) Learning about feelings; coping with peer pressure; coping with family relationships; coping with common problem situations.

"Bread and Butterflies"(4-9) Developing an identity; developing interpersonal skills; developing decision making skills; understanding the world of work, and one's vocational future.

"Self-Incorporated"(7-9) Developing an identity; coping with peer pressure; coping with family relationships; adapting to sexual maturity.

"On The Level"(9-12) Developing a sense of social responsibility; coping with peer and family conflicts; coping with personal changes; preparing for adulthood."

Betancourt, J. Am I Normal? New York: Avon Books, 1983.

This is based on the film by the same title and is intended for teenagers. The topic is male puberty, and the tone is light and humorous while at the same time accurate and thorough in presenting the issues and problems faced by adolescent boys as they experience their body changes.

Betancourt, J. Dear Diary. New York: Avon Books, 1983.

Also based on a film by the same title, this book covers the topic of female puberty in an equally lighthearted yet factually accurate manner.

Center For the Study of Social Acceptance. University of Mass., Downtown Center, Boston, 02125.

This center is involved in several projects which look at various components of social acceptance particularly with reference to handicapped children in the schools.

Some of the project members are developing an inservice program for teachers as well as courses at the university level. The *Social Skills Inservice Training Curriculum* is an unpublished teacher's manual which is being piloted in many schools in the Boston area.

Elardo, P. and Cooper, M. *Aware: Activities for Social Development.* Reading, Mass: Addison-Wesley, 1977.

This is a curriculum guide for use with middle elementary school children and includes 72 discussion activities which are grouped under four units: I. Getting Acquainted, II. Recognizing and Understanding Feelings, III. Understanding and Accepting Individual Differences, IV. Developing Social Living Behaviors. The goal of the program is to actively increase the childrens' ability to solve interpersonal problems, and to learn how to be more accepting of individual differences. The activity ideas and discussions appear to be lively and stimulate a positive non-threatening atmosphere which encourages social learning in a group setting.

Human Sexuality: A Portfolio for the Mentally Retarded. Planned Parenthood of Seattle-King County, Washington.

This is a portfolio of 10 drawings which is specifically geared for use with moderately retarded individuals. Each drawing has a desriptive text on the reverse side for use by the discussion leader.. The drawings are clear and accurate and on a scale that can easily by viewed by a small group. The drawings are as follows: 1. Girl to Woman, 2. Female Genitalia, 3. Boy to Man, 4. Male Genitalia, 5. Mann and Woman, 6. Men/Women - Different Body Shapes, 7. Male Masturbation, 8. Female Masturbation, 9. Sexual Intercourse, 10. Ways of Relating.

Nezer, H.W., Nezer, B. R., Siperstein, G.N. *Improving Children's Social Skills: Techniques for Teachers. (Teacher's Training Manual).* The Center for the Study of Social Acceptance. University of Massachusetts/Boston, 1985.

This manual consists of four units which cover the following topics: I. Understanding Social Development and Social Skills; II. Identifying and Assessing 'At-Risk' Children; III. Learning Approaches to Social Skills Training; IV. Improving Classroom Climate. The purpose of this program is to expand teachers' knowledge of social skills at both the theoretical and the practical level, thus enabling them to assist their students' social development in meaningful ways. It has been successfully used for in-service training workshops with guidance personnel, regular education and special education teachers. A useful list of curriculum materials, their content, price, and source, is also included. There is a companion manual which lists a variety of classroom activities for each unit. [*Improving Children's Social Skills: Techniques for Teachers. (Book of Activities.)*]

Seattle Rape Relief - Level I and Level II -- *Sexual Exploitation and Protective Techniques*. Available from Mass. Dept. of Public Health, Adolescent Health Office, 150 Tremont St., 3rd Floor, Boston, Ma. 02111.

This is a collection of film strips to be used with mentally handicapped individuals who are often victims of sexual exploitation. The filmstrips show what is acceptable behavior among people and what is not acceptable. At Level I the goals are to teach who is a friend and who is a stranger; how to use caution with a stranger; what are private parts of the body; how and when to say 'no'; and how to report sexual exploitation.

Stanfield Film Associates. P.O. Box 1983-C, Santa onica, Ca. 90406.

This company has produced several fine programs on sexual and social skills issues which include many visual and hands-on materials:

1. Sexuality and the Mentally Handicapped. Winifred Kempton has created a visually powerful set of 200 slides to be used primarily with mentally disabled individuals. The slides are real-life photographs which clearly depict the topic being presented. The 9 topics are: Parts of the Body, Male Puberty, Female Puberty, Social Behavior, Human Reproduction, Birth Control, STD's and Sexual Health, Marriage, Parenting.
2. Circles This program is for mildly to moderately retarded people ages 10 to adult and focuses on sexual and social distance and relationship building. The degrees of intimacy in interpersonal relationships is visualized in a system of six colored circles with the self at the center. Each additional circle that surrounds the center represents a more distant and thus less intimate relationship. Role playing is used extensively to give students practice identifying and modeling behaviors appropriate to specific relationships as represented by the circles. Included in the program are 155 slides, 19 teaching photos, and 5' x 5' Circles wall graphic.
3. Tips The publishers call this a "visual handbook for teaching social skills." It is a 7-part sound/slide series (525 slides) which teaches the skills critical for social survival. The parts are: I. Getting Along with Others, II. Getting to Know Others, III. Getting Along with Adults, IV. Having Friends, V.Enjoying Free Time, VI. Living in the Community, VII. Being on the Job.

Stephens, T.M. Social Skills in the Classroom. Columbus, Ohio: Cedars Press, 1978.

The materials and ideas in this book were designed to be used with a 'directive teaching' approach in which a target behavior is identified, student level of functioning is assessed and then specific teaching strategies are prescribed to fit the student's particular needs. There is a social skills check list of 136 skills that have been identified by teachers and researchers as particularly important for success in the classroom. There are many ideas for each type of teaching strategy with additional references for supplemental classroom materials. This is a very detailed and thorough resource which can be used in a variety of settings within a school or, with adjustment, in other locations.

Articles and Books on Social Skills

Berler, E.S., Gross, A.M., and Drabman, R.S. "Social Skills Training With Children: Proceed With Caution." Journal of Applied Behavior Analysis. 15:1, p. 41-53, 1982.

Report on research with 3 learning disabled boys who were given social skills training two or three times a week for 5 weeks. Although the results showed that the subjects did learn the skills being taught when evaluated in follow-up sessions, the positive changes did not generalize to the natural school setting. The researchers discuss the possible reasons for this, some of which had to do with experimental design constraints, and some of which, they suggest, might be caused by the difficulty of transferring skills learned in isolation to the natural environment. Thus, the conclusion is "proceed with caution" when considering the use of formal social skills training programs.

Bernstein, G.S. "Research Issues in Training Interpersonal Skills for the Mentally Retarded." Education and Training of the Mentally Retarded. 16:1, pp. 70-74. 1981.

Suggests that when analyzing interpersonal behaviors, researchers should focus on 5 dimenions: content, intersubjective, extralinguistic, relationship, and setting. The author also observes that when identifying social competencies, the problem may lie in the quality level of the skill(s) rather than in the lack of possessing the skill.

Cartledge, G. and Milburn, J.F. Teaching Social Skills to Children. New York: Pergamon Press, 1980.

This book provides an excellent introduction to the major ideas and topics of social skills education. A conceptual framework is provided in the section on theories of development which is followed by a clear delineation of how social skills are identified via inventory check lists. Chapter 2 covers a variety of assessment and evaluation techniques. Teaching methods are thoroughly reviewed in Chapter 3, while the importance of assuring that the skills learned will be generalized into other settings is highlighted in Chapter 4. Part II offers a variety of approaches used with different special populations and an extensive annotated resource bibliography further strengthens this book as a comprehensive look at recent thinking in the field of social skills education.

Davies, R.R. and Rogers, E.S. "Social Skills Training with Persons Who are Mentally Retarded." Mental Retardation. 23:4, pp. 186-196, 1985.

The authors believe that effective social behavior consists of four behaviors and skills: nonverbal, verbal, affective, and social cognitive skills. Their article reviews and attempts to classify the results of approximately 30 social skills training programs. They have concluded that several important aspects of social skills training have been inadequately investigated to date. For example, active rehersal, contingent reinforcement, and active programming for generalization have not been integral parts of many studies. A glaring omission was found in that most of the studies they reviewed did not assess the social impact or validity of teaching social skills. This left the crucial question -- "Is the subject's social life improved as a result of the training program?"--unanswered.

Elardo, P.T., and Caldwell, B.M. "The Effects of an Experiental Social Development Program on Children in the Middle Childhood Period." Psychology in the Schools. 16, pp. 93-100, 1970.

The authors developed a curriculum called Project Aware which purports to improve the role-taking and social-problem-solving skills of elementary school children. The more general goal is to create a classroom atmosphere of mutual respect and concern among students. The curriculum was then taught by two fourth and fifth grade teachers for about six months to 34 children. Results were compared with a control group of matched subjects, and showed significant improvement in the experimental group on the variables tested: showing respect and concern for others, generating alternatives to a story situation, patience, self-reliance, and creative-initiative.

Elias, M.J. and Maher, C.A. "Social and Affective Development of Children: A Programmatic Perspective." Exceptional Children. 49:4, pp. 339-346, 1983.

The authors discuss the importance of developing the social and affective domains for both handicapped and non-handicapped children in the mainstream school classroom. They report on an approach using a television-based instructional format that includes television(and other audiovisual media), discussion, and role playing (or other experiential activities). Specific program titles which are currently available from the Agency for Instructional Television are recommended for use at different grade levels.(See Curriculum Materials section.)

Gaylord-Ross, R., Haring, T., Breen, C., Lee, M., Pitts-Conway, V., and Roger, B. (Eds.) The Social Development of Handicapped Students. San Francisco State University, 1984.

The majority of research in this monograph came from the Socialization Research Project, Special Education Department, San Francisco State University, which was sponsoredby the US Department of Education. The nine articles report on research dealing with interaction patterns of handicapped and non-handicapped students as they mingle in the natural setting within schools, work and the community. The article,"Social Skill Training in Natural Contexts" by Gaylord-Ross, Stremel-Campbel and Storey is especially interesting as it reviews the effects of training in different educational domains: communication, leisure, social-sexual, community and vocational.

Gresham, F.M. "Misguided Mainstreaming: The Case for Social Skills Training with Handicapped Children." Exceptional Children, 48:5, pp. 422-433., 1982.

This paper asserts that mainstreaming has been partly based on the faulty assumption that placing handicapped children in regular classrooms will automatically result in improved social interaction and acceptance among handicapped and nonhandicapped children. The author extensively reviewed studies which refute these assumptions, and suggests an alternative approach whereby handicapped and nonhandicapped children are encouraged and taught effective social skills.

Gresham, F.M. "Social Skills Assessment as a Component of Mainstreaming Placement Decisions." Exceptional Children, 49:4, pp. 331-336, 1983.

The author's stated position is that information on a child's social skill level may be a more relevant factor in determining a mainstream placement than IQ or academic achievement. The author advocates a multidisciplinary team approach to assessment which would include regular and special education teachers, as well as parents. The actual assessing would be carried out via teacher ratings (Stephens Social Behavior Assessment is recommended), sociometric measures, and naturalistic observations.

Gresham, F.M. "Social Skills Instruction for Exceptional Children." Theory Into Practice. 21:2,pp. 129-133, 1982.

An important idea presented in this article is the conceptualization of social skill deficiencies as occuring in three dimensions: skill deficits (i.e. lack of possessing the skill), performance deficits (i.e. possessing the skill but using it poorly) and self-control (i.e. impulsive behavior interferes with both skill acquisition and performance). Various training approaches have been found to be particularly effective with each of these dimensions and the author elaborates on these in the remainder of the article.

Gresham, F.M. "Social Skills Training With Handicapped Children: A Review." Review of Educational Research, 51:1, pp. 139-176, 1981.

This is a thorough critical review of the literature on social skills training for handicapped children. The author pinpoints several areas of deficiency in the existing literature which should be addressed in the future. These include: how social skills are selected to be studied and their impact on the children; which social skills are best suited to which setting; how much generalization and maintenance of trained social skills occurs subsequent to the training period; what is the role of training nonhandicapped children in acceptance and interaction with handicapped children; and are certain social skill techniques more successful with particular types of handicap.

Gresham, F.M. and Nagle, R.J. "Social Skills Training With Children: Responsiveness to Modeling and Coaching as a Function of Peer Orientation." Journal of Consulting and Clinical Psychology, 48, pp. 718-729, 1980.

This article reports on a study done with 40 socially isolated children in the third and fourth grades. The researchers employed sociometric and behavioral measures to study the effects of one of four social skills training conditions (coaching, modeling, mixed abbreviated modeling and coaching, and control). Classroom peers were chosen and trained by the experimenters in the social skill techniques which were to be shown on the videotapes during the experimental training sessions. The results showed that all three training methods were generally effective in increasing the isolates' peer rating on the sociometric measure which measured how much other children in their classes would like to play with them. No increases were found on the work-with sociometric rating which is probably due to the fact that the video and training sessions occured using play situations. The authors call for more research and assessment in the area of social skills training for children who are lacking the interpersonal skills necessary for effective functioning in a peer group.

Hughes, J.H., and Hurth, J.L. Handicapped Children and Mainstreaming: A Mental Health Perspective (A Review of Model School Programs and Practices.) Publication # (ADM) 84-1361.

Available from: U.S. Department of Health and Human Services
Public Health Service
Alcohol, Drug Abuse and Mental Health Admin.
Natl. Institute of Mental Health
5600 Fishers Lane
Rockville, Md. 20857

This is a very handy review of programs around the country which have unique and exemplary qualities.

Johnson, R.T. and Johnson, D.W. "Building Friendships Between Handicapped and Nonhandicapped Students: Effects of Cooperative and Individualistic Instruction." American Educational Research Journal, 18:4, pp. 415-423, 1981.

This study looked at the effect of two types of instruction--cooperative and individualistic--on the interaction patterns between forty handicapped and nonhandicapped third-grade students in a regular classroom. Both during and following the instructional situation (which was a unit in math), sociometric recordings were made by trained observers, and a questionnaire was completed by each student. The results indicated that cooperative learning promotes more cross-handicapped interaction both during instruction and in post-instructional free time than individualistic learning experiences. The authors feel that their results have important implications for educational practice particularly with regard to mainstream classrooms where handicapped and nonhandicapped children are studying and playing side by side. An emphasis on cooperative activities, both educational and recreational, will build patterns of interactions that will encourage reciprocal rather than parallel relations.

Johnson, R.T. and Johnson, D.W. "Effects of Cooperative, Competitive, and Individualistic Learning Experiences on Social Development." Exceptional Children. 49:4, pp. 323-329, 1983.

In this study, the researchers pursue the same question as in their previous study(1981) with some further expansion and refinement of their original hypothesis. This time, the fifty-nine subjects were fourth graders, and there were three experimental conditions--cooperative, competitive, and individualistic. Proximity during free time was used as a dependent variable in this study, rather than cross-handicap interaction during free time(1981 study), and perspective-taking ability was a new variable in this study which involved asking non-handicapped children to pretend they had a learning problem and then tell a story about a typical school day for them. The results support the earlier findings that cooperative learning experiences promote more interpersonal contact between handicapped and nonhandicapped students than do individualistic and competitive ones. Also, this study found that cooperative situations promote higher self-esteem on the part of all students (handicapped and nonhandicapped) and greater perspective-taking ability on the part of nonhandicapped students than did competitive situations.

LaNunziata, L.J., Hill, D.S., and Krause, L.A. "Teaching Social Skills In A Classroom for Behaviorally Disordered Students." Behavioral Disorders. 6:4, pp. 238-246, 1981.

Four students enrolled in self-contained classrooms for the Behaviorally Disordered were selected by their teachers for inclusion in this social skills training program. The procedures used followed Stephen's Social Skills in the Classroom and were implemented by the classroom teachers with the assistance of the researchers who provided an in-service workshop training and classroom support via consultation and observation. Improvement occured in all targeted behaviors and functional relationships were established between teaching strategies (social modeling, contracting, and social reinforcement) and several targeted behaviors (distractions ignored, on-task behavior, and percentage of neat papers). The researchers conclude that Stephen's curriculum is a highly valuable tool for teaching social skills in the classroom. (This article does not report on any carry over of what was learned in the self-contained classroom into a less restrictive setting.)

McCauley, R.W., Bruininks, R.H., and Kennedy, P. "Behavioral Interactions of Hearing Impaired Children in Regular Classrooms." Journal of Special Education. 10:3, pp. 277-284, 1976.

This was a follow-up to an earlier study done on the same hearing impaired children when they were in the first and second grades. This time the focus was on comparing the interactive behaviors of the hearing impaired children with nonhandicapped children in the same classrooms. It was an exploratory study and was based on observers rating interactive behaviors during several observation periods. Although there were no significant differences found between the hearing impaired and nonhandicapped children with regard to positive and negative interactions within the classroom, the there were quantitative differences. For example, hearing impaired children directed more verbalizations to their teachers than did nonhandicapped children, whereas nonhandicapped chilren directed more verbal interactions toward their peers than did the hearing impaired children. The researchers conclude that the teacher is a prime source of support for hearing impaired children, especially when teacher/child interaction is positive.

McClure,,L.F., Chinsky,J.M., and Larcen, S.W. "Enhancing Social Problem-Solving Performance in an Elementary School Setting." *Journal of Educational Psychology.* 70:4, pp. 504-513, 1978.

The purpose of this study was to clarify both the theoretical and practical relationships between social problem solving, social performance, and social adjustment in an elementary school setting. The subjects were 185 boys and girls in the third and fourth grades. The experimental design used four training groups: no treatment (control), video modeling tapes (television), video modeling tapes plus discussion exercises (discussion), and video modeling tapes plus role-play exercises (role play). The training program consisted of six components: problem-solving orientation, problem identification, alternative solutions, consideration-of-consequences, elaborations, and integration. The findings generally indicated that the role-play treatment is more likely to transfer to everyday social interactions and to enhance children's social competence.

Michelson,L., Foster, S.L., and Ritchey, W.L. "Social-Skills Assessment of Children." In *Advances in Clinical Psychology.*Vol. 4. Lahey, B.B. and Kazdin,A.E. (Editors). New York: Plenum Press, 1981.

This is a very thorough review of assessment procedures, instruments, and terminology used by social skills investigators over the past ten years. The discussion focused on the following areas: the parameters used in assessing socially skilled behaviors; the value judgments implied in qualitative definitions of "acceptable" behavior; the various methods of assessment such as role play, ratings by significant others, self-report measures, and naturalistic observation; and evaluation of assessment tools with regard to normative data, external reliability, inter-rater reliability, objectivity, relationship to *in vivo* behavior, long-and short-term outcomes, and applicability to different age groups. The authors conclude that it is imperative for researchers analyzing children's social skills to employ a wide variety of assessment strategies in order to effectively and accurately measure the level of competence and detect problem areas.

Michelson, L., Sugai, D.P., Wood, R.P. and Kazdin, A.E. *Social Skills Assessment and Training with Children.* New York: Plenum Press, 1983.

This book is aimed at professionals who want to carry out systematic social skills training programs. There is detailed information on issues and methods of assessment, types of social skills training approaches, 16 specific teaching modules (or lessons), and logistical issues in planning and implementing training programs. There are very useful appendixes on Sample Assessment Instruments, and Social Skills Films for Children. The authors have integrated a variety of clinical and research findings into an effective program for promoting social skills growth in children.

Nezer, H.W., and Nezer, B.R. *Improving Children's Social Skills: Techniques for Teachers (Book of Readings).* Compiled by Center for the Study of Social Acceptance, University of Massachusetts, Boston.

A collection of thirteen articles which give the interested teacher an overview of the current research and thinking in the field of social cognition and social skills development.

Oden, S. and Asher, S.R. "Coaching Children in Social Skills for Friendship Making." Child Development. 48, pp. 495-506, 1977.

In the first experimental condition in this study, third- and fourth-grade socially isolated children were coached in selected social skills. They were then introduced into a play situation with a peer to practice the skill, following which the coach reviewed the play-session with them. In the second condition (peer pairing), isolated children played the same games with the same peers but did not have the previous coaching instruction. In the third condition (control), isolated children were taken out of the classroom with the peer, but each played solitary games and did not interact or receive coaching. The final results indicated that the socially isolated children who received coaching improved significantly more than the peer-pairing and control groups on a play sociometric rating scale. These same children showed continued progress in a follow-up assessment one year later, a finding which particularly pleased the researchers since previous studies had not been found to produce lasting effects. There was, however, no generalization of these social skills acquired in a play setting to the work setting.

Santomier,F. and Kopczuk, W. "Facilitation of Interactions Between Retarded and Nonretarded Students in a Physical Education Setting." Education and Training of the Mentally Retarded, 16:1, pp. 20-23, 1981.

Nine mentally retarded seventh grade students were paired with nine nonretarded students and randomly assigned to one of three physical education treatment conditions: (1) control group (teacher praise for motor skill performance); (2) experimental group I (teacher intervention and teacher praise for motor skill performance); (3) experimental group II (teacher intervention and teacher praise for social intervention). Observers coded the number of social interactions occuring in each condition. The 15 minute sessions were divided into three segments: introduction to the play equipment, video-taped free play, and teacher directed physical activities. The results showed a significantly higher rate of social interaction occured in experimental condition II where there was praise given for social interaction. The researchers conclude that merely pairing retarded and nonretarded does not ensure social interaction. What this study does not show is who initiated the interactions, whether they were positive or negative, whether there was transference of interactions into other settings, and whether the increased interaction was still noticeable over time.

Schmuck, R.A., and Schmuck, P.A. Group Processes in the Classroom, Dubuque, Iowa. Wm. C. Brown Co., 1975.

A useful book with many ideas for extablishing a positive climate in the classroom. The relationship of the sequential stages of group development is particulary interesting. Several theories are described.

Schulz, J.B. and Turnbull, A.P. Mainstreaming Handicapped Students: A Guide for Classroom Teachers. Boston: Allyn and Bacon, Inc. 1983.

This book focuses on the educational characteristics of many types of handicapping conditions.

Selman, R.L. "The Child As Friendship Philosopher." In Asher and Gottman(1981) (See Background Information, p. 1) pp. 242-272.

The author reviews some of the recent literature on the developmental aspects of friendship formation, and discovers several common threads which lead into his own research on the perspective-taking-ability of children at different ages. His own approach starts with generating a structural-developmental theory of social cognition and then attempting to see if empirically observed data bears any reliable relationship to the theory. There are very good descriptions of the three phases of the research (constructing the model, validating the model, and applying the model), the developmental levels and stages of friendship, important issues in the friendship domain, and future directions for research. Of particular interest is the notion that a structural-developmental model should be useful for understanding the developmental aspects of social behavior and functioning, especially when the social skills of a child are not age-appropriate or situation-appropriate.

Selman, R.L. "Toward a Structural Analysis of Developing Interpersonal Relations Concepts:Research with Normal and Disturbed Preadolescent Boys." In A.D. Pick. Minnesota Symposia on Child Psychology. Vol. 10. Minneapolis: Univ. of Minn. Press, 1976.

The main components of Selman's structural-developmental approach are explained via references to his two studies with normal and disturbed preadolescent boys. The guiding principle of his research is that "social perspective taking, defined as the developmental process by which the child constructs and comprehends the relation of the perspectives of self and other(s), is the basic structural component of reasoning about certain social categories of experience, particularly reasoning about interpersonal relations." He discusses the five levels of social perspective taking inferred or observed in his research so far, and relates these to the development of conceptions about interpersonal relations. Data from the studies is thoroughly presented and analyzed. The article concludes with a summary of what the evidence to date has shown and what new areas of research are suggested by it.

Spivak, G. and Shure, M.B. "The Cognition of Social Adjustment." Advances in Clinical Psychology, Vol. 5. B.B. Lahey and A.E. Kazdin (Eds.) New York: Plenum Press, 1981.

The authors present a detailed summary of their clinical and research work over the past decade in which they, and others, have attempted to identify and measure a set of thinking processes which they call interpersonal cognitive problem-solving skills (ICPS). In this article they outline the theory and assumptions underlying their work, describe the ICPS skills that have been identified to date, introduce the idea of non-ICPS thinking, and describe several training programs which have been found to enhance ICPS thinking. The ICPS skills they describe are: (1) the capacity to generate alternative solutions to problems; (2) the ability to consider the consequences of one's social acts in terms of their impact on other people and on oneself; (3) the ability to mentally articulate the sequence of steps that may be necessary to carry out a solution to a particular interpersonal problem; (4) the degree to which a person understands that a present problem has been determined by prior events; (5) the ability to understand and articulate the variety of problems inherent in interpersonal encounters, which they call "sensitivity to problems"; and (6) the ability to see that surface behavior may mask underlying issues and motives, which they call "dynamic orientation."

Stainback, W., Stainback, S., Raschke, D., and Anderson, R.J. "Three Methods of Encouraging Interactions Between Severely Retarded and Nonhandicapped Students." Education and Training of the Mentally Retarded. 16:3, pp. 188-192, 1981.

The authors describe several approaches which have been found to be effective in encouraging interactions between handicapped and nonhandicapped children in the mainstream classroom. These include: (1) classroom organization techniques such as small heterogeneous groups which emphasize cooperative activities, and use of materials and toys which encourage interaction; (2) training programs for the retarded students which teach specific social interaction skills; and (3) motivating the nonhandicapped students to interact with the retarded students, an area which needs more research to develop effective approaches. This article has some interesting ideas, but does not provide much depth in covering the topic.

Strain, P.S. (Editor) Social Development of Exceptional Children. Rockville, Md: An Aspen Publication, 1982.

This is a wide ranging collection of 14 articles from a variety of journals each of which deals with some aspect of the social development of handicapped children. Home, school and community settings are represented and throughout most articles there is a strong focus on the stages of development a child and family encounter in their lives together.

Family Support

Editor's note:

We are grateful to Jo Bower, Associate Planner for the Massachusetts Developmental Disabilities Council, for contributing the following paper on Family Support.

THE COMMONWEALTH OF MASSACHUSETTS
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EXECUTIVE DIRECTOR

MEMORANDUM

TO: All Interested Persons

FROM: Jo Bower JB, Associate Planner

RE: Family Support -- An Introduction

DATE: February 1987

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I. INTRODUCTION

In keeping with the Council's long-term objective of developing the concept of a "Lifetime Service Plan," and in conjunction with our case management service priority, I have been researching the state of the art across the nation in the area of family support systems.

Family support can be defined as the coordination and delivery of those services which are necessary for persons with developmental disabilities to live a normal community life with their families. Family support encompasses services to an entire family unit.

Researchers estimate that 75-90 percent of all persons with developmental disabilities live with their families. Historically, the needs of these families have been unrecognized by a service system largely focused on the provision of institutional services. Family support is not

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only a means to prevent institutionalization, but can be a catalyst for more deinstitutionalization as well. Moreover, as community-based services have developed, providers have not always involved families as much as they might.

> "The only way to change paradigms is to legislate, litigate, agitate, and bury the dinosaurs." C. Wieck, Minnesota Developmental Disabilities Council.

Although families in Massachusetts have benefited from the growth of respite care and other support services from various state agencies, these developments represent only the "cutting edge" of what is needed to fully support families. These families experience not only the stress of caring for a person with disabilities, who may have complex medical, nutritional and/or physical needs, but also the frustration of dealing with a fragmented, uncoordinated, inadequate service system. This situation sometimes leads to family crisis and unnecessary out-of-home placement for the person with disabilities.

> "It is truly outrageous that if we place Adam outside our home, he will receive more services than we can get if we keep him at home." A parent.

The concept of "family support" has been endorsed in many states across the nation, and several major studies on family support policy and programmatic issues have been completed.

A major resource for what follows is a study completed in May 1986 by the Human Services Research Institute entitled, "Family Care for Persons with Developmental Disabilities: A Growing Commitment." Many of the questions/issued raised below are framed as a result of reference to this document, and I am grateful to the staff of HSRI for their good work.

The remainder of this memo is divided into 5 sections. It is intended to provide background, and raise issues and questions for further discussion. The Council is currently studying the concept of Family Support and collaborating on the development of a major policy initiative for Massachusetts, as one piece of a "Lifetime Service Plan" for all persons with developmental disabilities. A statewide family support system is highly compatible with all the Council's and the developmental disabilities movement's priorities and objectives.

II. WHAT IS FAMILY SUPPORT?

Family support services can be generally viewed as those services, in addition to core residential arrangements, which are necessary to enable developmentally disabled people to live a normal community life with their families. Family support is also viewed as a means not only to prevent institutionalization, but a catalyst for more deinstitutionalization as well. Family support encompasses services to an entire family unit, to enable it to maintain their member with a disability in the home environment.

The services included under the rubric of family support are many and varied. Seventeen states currently have some kind of family support enabling legislation. Many other states are in the pilot/demonstration phase of developing comprehensive family support services (see Section IV). Massachusetts provides several services to families of developmentally disabled individuals, including respite care; and numerous other services to certain subsets of the developmentally disabled population itself, but the Commonwealth has no legislation establishing a network of family support services for the developmentally disabled population as a whole.

It is important to note that case management is an important component of some established family support programs; and that this function generally serves to access and coordinate other services which the disabled person needs. Massachusetts' (limited) case management capabilities are scattered across a variety of state agencies. One of the Council's goals (in the federal service priority area) is to explore ways to institute a more comprehensive, cross-agency system.

"Formal" family support programs in other states offer direct services, cash assistance or both, to assist a family in obtaining the particular services it needs to maintain its severely disabled member at home.

Some combination of the services listed below are customarily included in state-sponsored family support programs:

diagnostic and evaluative procedures
purchase of special equipment
companion services
respite care
housing modification
counseling for the client and/or family
medical/dental care not covered by insurance
special diets and nutritional consultation
specialized therapies
home health care
special clothing
recreational services
special transportation
case management
personal care attendants

A growing number of policy makers, planners and advocates in Massachusetts are recognizing the needs of families who care for persons with developmental disabilities, and the necessity for a comprehensive family support system in the Commonwealth which will be fiscally responsible, programmatically sound, and above all, responsive to family needs.

III. THE STATUS OF FAMILY SUPPORT IN MASSACHUSETTS: CURRENT SERVICES AND PROGRAMS

1. Respite Care

Respite care allows family members to "take a break" from the ongoing demands of caring for a disabled individual. It reduces emotional stress, decreases the possibility of abuse or neglect, and diminishes the potential for institutionalisation. It can be provided in the family's home, a private provider's home, or in a facility.

Three state agencies provide funding to a variety of private agencies which, in turn, provide various types of respite care to families. The Department of Social Services (DSS) pays for up to 10 days of respite care in each six month

period to families of individuals with developmental disabilities. (DSS Respite care is the only service in the state which uses the federal definition of developmental disabilities as a basis for service eligibility.) The Department of Mental Health (DMH) also funds respite care, chiefly for adult clients whose primary diagnosis is mental retardation. The Department of Public Health (DPH) arranges and pays for a limited amount of respite at pediatric nursing homes for families of medically involved, multiply-handicapped children.

> "What we want is the opportunity to live the way other families do: to go to a movie on Saturday night, take a course at a community college, run a bake sale at church." A parent.

2. Specialized Home Care

DMH provides "specialized home care" to individuals with developmental disabilities and their families. The service began as a foster care program and has since added the capacity to provide in-home supports to biological families in the areas of behavior management, leisure activities, activities of daily living, etc. There is no uniform service model; different DMH areas take different approaches. Specialized home care serves approximately 330 persons with specialized foster care and another 300 persons with in-home supports.

DPH also pays for home care to medically involved children living at home. Home health care agencies provide these services, which are structured flexibly to meet families' needs.

3. Early Intervention

DPH contracts with about 45 programs to provide early intervention services to children ages birth to 3 who have or who are at risk of developmental delay. This service model has a family focus, and assists the family to better care for their child's needs. Unfortunately, the service is not an entitlement and thus not available to all who need it.

4. Generic and Private Services

Generic services are another important piece of any family support system. Massachusetts has some generic services which are available and accessible to families with members who are developmentally disabled, but there are many community resources which are as yet untapped, or have not made themselves truly accessible to individuals with severe handicaps.

Examples of "generic" state agency services which are available to families of persons with developmental disabilities are DSS' substitute care, day care, parent aides, etc.; these services are available to families who qualify by income, or by the fact that their children are known to the Department. Also available are DSS' protective services, directed toward children in the Commonwealth who are at risk of abuse and neglect.

Some local communities also offer programs for persons with developmental disabilities through municipal recreation departments, or truly "generic" agencies such as the YMCA. However, many agencies without a special knowledge in dealing with persons who have disabilities have been reluctant to initiate such programs and in some areas there is a serious lack of social and recreational opportunities, as well as transportation to whatever activities may exist. Some school departments have also enlarged their programs to include extra-curricular and adult education opportunities, but these opportunities are available only in some localities, and often on a very limited basis. There has never been a systematic statewide survey identifying exactly to what extent these services exist, or are needed.

Local private, non-profit agencies, such as Associations for Retarded Citizens, have actively organized and promoted a wide variety of activities for persons with disabilities. These services range from after-school activities and special trips, to an array of parent support, and self-advocacy groups. Parents have often been the driving force behind the development of these agencies and their services.

5. Case Management/Service Coordination

> "...parents often search widely for the best possible service resources. The parent can be consumed fully in the role of agent on behalf of the disabled child." Darling, 1979.

Case management/service coordination is an important component of family support. Families needing more than one service from more than one agency frequently need assistance in finding services and coordinating their delivery. Some families also need support in learning how to be case managers themselves, so that they can carry on should professional case management be interrupted or unavailable.

6. Parent Support Groups

A number of local advocacy groups (some of which are referenced below) sponsor parent support groups, to enable families with members who are disabled to share information and support one another. These groups have been tremendously helpful to families by enabling them to solve problems by talking with other parents who may have faced and solved similar problems.

7. Advocacy Resources

Some advocacy resources are available to parents and families needing them. The Federation for Children with Special Needs provides technical assistance and training to parents and parent groups on a variety of topics, including the special education laws, how to work productively with human services professionals, and how to be an effective advocate. It also provides information and referral for parents seeking programs and/or program information for their disabled family member. The Federation also sponsors a special telephone advocacy service (funded by the Council) to help individuals who may be eligible for services under the "Turning 22" Law. The Federation also has strong linkages with a variety of other advocacy groups.

> "If we as agency providers fear the process of empowerment...we will destroy our ability to allow parents to take charge of their lives and to manage the care of their disabled child." A service provider who is also a parent.

The major source of advocacy from within state government is the Help for Children program of the Office for Children, including assistance with special education problems.

IV. FAMILY SUPPORT PROGRAMS IN OTHER STATES

The Wisconsin Council for Developmental Disabilities recently completed a nationwide survey of "family support services" in 48 states. Support programs were identified to include:

1. economic incentives to adoptive parents of "difficult-to-place" children;
2. direct subsidies to families for the costs of care;
3. technical assistance to families;
4. respite care;
5. training to families with institutionalized members, as a prelude to bringing the disabled family member home.

In general, there is wide variability in how these programs are designed, their capacity, eligibility, administration, services provided, etc.

Some states limit eligibility according to age, or by severity of the disability. Family cash subsidies seem to range around $200 per month and up.

Michigan estimated that its program achieved significant cost savings: institutional per day per person costs averaged $137 in FFY 1983, while the subsidy program cost $7 (per person) for the same period.

Pilot programs have often been funded by the state DD Council. Once a program is functioning and shown to be effective, state legislatures seem more willing to grant allocations to family support. Across all the states surveyed, legislative appropriations ranged from $23,000 (CT) to $4,000,000 (MI) for a given fiscal year. Programs serve between 50 and 800 families per year.

I have chosen five state programs to summarize below. Maryland, which provides support services and Michigan, which has a combination cash assistance/support service offer examples of what two mid-size industrial states have established. (Michigan is also considered a model state.) Rhode Island illustrates how a small-scale cash assistance program can be established. Wisconsin, with a combination program, is also a "model state" and Pennsylvania has the oldest, formally designated "family support program" in the nation.

A. Maryland

Maryland's family support legislation was enacted in 1984 and was funded by the DD Council there at a level of $210,000. For the current fiscal year, the program has been level-funded, but the state is assuming half the cost ($110,000). The program limits eligibility to persons under age 22 who are in out-of-home placements or at risk of same.

Nine services are covered under the program, including individual and family counseling, personal care, day care, specialized equipment, health services, respite care, housing adaptations, transportation and other needed services. Services are provided by the responsible state agency (Department of Health and Mental Hygiene) contracting with appropriate private, non-profit agencies. The local agency is then responsible for coordinating and assisting the family in using all services which are already available under other programs.

B. Michigan

Michigan has two family support programs: cash assistance and support services. The subsidy program was created in December 1983 and the support services were initiated as part of a pilot project in 1978 and expanded to cover the whole state in 1984.

In Fiscal Year 1985, the Michigan Legislature appropriated $4 million for support services and $4.5 million for cash assistance.

The support services are available to all families of disabled individuals, regardless of the person's age. Additionally, there are no income limitations, although the actual services are available on a sliding fee basis. There is no limitation on what services may be used, but it has been found through survey activity that the most frequently used services are: special equipment, medical expenses, special diets, nutritional counseling, respite care, parent training, housing adaptations, diagnostic assessments, case management, and in-home assistance.

To be eligible for cash assistance, a family must have: (a) taxable income of $60,000 or less; and (b) a child under 18 living at home who has been determined by an interdisciplinary team to be severely mentally impaired, severely multiply impaired, or autistically impaired. Families must submit a tax return annually and reapply for the subsidy each year. Every family found eligible for a subsidy receives $225 per month.

If a family wishes to prepare to bring a family member home from an institution and care for him/her at home, they would be eligible for a one-time payment of $550.

The cash assistance program is intended to complement, rather than supplant existing public assistance or social service payments. The costs of this program are paid 90 percent by the state and 10 percent by the local county. Implementation of these programs has been carried out by the Department of Mental Health. The community mental health boards determine eligibility of applicants. Parents must report to the county mental health program annually on how they have spent the subsidy. It has been estimated that the cost of the subsidy program is $7.41 per person per day compared to $137 for institutional care, and that if one child is enabled to leave an institution or prevented from entering one, the cost savings are $47,000 per child per year.

C. Pennsylvania

Pennsylvania's Family Resource Services program is the oldest family support program in the nation. Enabling legislation for the program was passed in 1972, and $700,000 was appropriated that year. The Fiscal Year 1984 appropriation was $3.6 million, providing services to 13,000 persons at an average per family (or individual) cost of $1,734.

Under Pennsylvania's broad eligibility guidelines, the following groups of persons are eligible: (1) mentally retarded persons who are living at home with natural, adoptive, or foster families; (2) mentally retarded persons living independently in the community; and (3) natural, adoptive or foster families who are maintaining a mentally retarded person at home. There are no age limits.

Services are provided on the basis of need, funding, and availability. They include: a wide variety of in-home therapies, recreation/leisure time activities, respite care, homemaker services, family education/training, family aid (babysitting), mobility training, home adaptations, special diets, and special innovative services (which require prior approval).

However, not all of these services are available in all parts of the state. Because the program is administered on a county basis, there are wide disparities across the state in the number and amount of services available for families (or individuals).

D. Rhode Island

Rhode Island has a small cash assistance program which is helpful to examine as a potential pilot for a larger state. In FY 1984, the Legislature appropriated $256,000 and served 66 families. These funds represent a mixture of state, federal

(Title XIX waiver) and private resources. The grassroots advocacy community played a pivotal role in working with the Legislature to initiate this program in 1977.

The purpose of the cash assistance was originally to encourage parents to bring their disabled sons/daughters home from state institutions. Since its inception, however, its purpose has expanded to include the avoidance of placement and to enhance the family's caretaking ability. An early intervention program has been started to complement the subsidy and to discourage out-of-home placements.

In order to receive cash assistance, the disabled family member must be mentally retarded and must meet the admission criteria of the public institution OR the family must be experiencing difficulty in providing necessary care. There is no age limit. Subsidy payments for basic care of the individual range from $25 to $75 per week ($1,300-$3,900/year). Additionally, payments to support training of the individual are available in amounts ranging from $5 to $15 per week ($260-$630/year).

The payments may be used to pay for the following services: case management, adaptive equipment, medical/dental services, educational/therapeutic services for the disabled person, housing modifications, respite care, family training or counseling and homemaker assistance.

E. Wisconsin

Wisconsin is another state which has a combination of support services and cash subsidies for families. It was signed into law earlier this year (1985) and there is a $300,000 appropriation for FY 1985, which is estimated to be adequate to serve 400 families.

The goals of the Wisconsin program are to promote opportunities for the care of disabled children in home environments, reduce the necessity for out-of-home placements, enhance the quality of life for these children and their families, to increase availability and coordination of needed services and to increase parental control in directing the service to be provided.

The eligibility criteria for these programs includes a definition of disability which closely follows the federal DD definition, and an age limitation of under 21. The disabled person must be living in a "family" which is defined as a group that lives together and consists of at least one disabled child and the parent(s). A "parent" may be a birth or adoptive parent or guardian, or a "person acting in place of a parent," (e.g., those who provide care in group homes)

An extensive and impressive array of services are included in this program. Supplemental payments are $3,000 per child per year. The benefit level is determined by a combination of factors which include income, family size, number of disabled children, and medical and other expenses of the disabled child. The program is administered through the county mental health system.

V. FAMILY SUPPORT IN MASSACHUSETTS--CURRENT ISSUES

A. Plymouth DMH Area Pilot Project--One Approach

Some of the family support services described above are already offered in Massachusetts; one on a statewide basis (respite care) and others on a more limited basis, such as specialized foster care and assistance for cognitively limited families.

The DMH Plymouth Area has made a concerted effort to use new program monies to develop family support services. These include a transportation program for mentally retarded adults, parent support groups, and a resource directory. These services are overseen by a parent steering group. The funding level for these programs is currently at $35,000. The vendor is The Web of Life, Inc., an outdoor education agency which also sponsors two staff apartments for mentally retarded people.

The services included in the family support contract were chosen for development based on a survey sent to 300 parents and other professionals working with mentally retarded clients. Clients and/or families will pay for the transportation provided, approximately $3 for a trip from Plymouth to Hanover based on full utilization of the van. The actual transporting of clients will be sub-contracted by The Web of Life to a transportation vendor.

B. Components--What's Needed?

In looking at the components which need to be included in the system, it will be necessary to ascertain which services already exist in parts or all of the state; and then to develop a means by which these services can be coordinated into an integrated network. Critical gaps in service need to be identified, so that necessary new service components can be developed.

It is also important to determine what is the most critical barrier to service for families when designing family support. In the Plymouth area, it seemed to be the issue of supervision. Aging parents of DD individuals are reluctant to allow their children to go out on their own, even if they are able to do so independently. Other clients will need supervision in the community.

The issue of whether to provide direct services, or to provide cash assistance, or both, is also important. The advantage of cash is the control it gives to the family in purchasing the service(s) it needs. The disadvantage may be the confusion that results if parents do not know what is available and/or appropriate for their son/daughter, or if the needed service is not available.

C. Eligibility--WHO?

The question of who should receive services is also critical.

1. Should family support be provided in the form of a few services to many families?
2. Should family support be provided with many services to all (?) families?
3. Should family support be provided to the most "needy" families; and should these families be offered a few services or many services?

What constitutes "need" and whose need is to be addressed? A family's need is different from an individual's need.

D. Administration--HOW?

There are additional issues having to do with administration. Should family support be administered on thelocal level or on a central level? Issues of access and equity must be evaluated. The structure of services and access mechanisms must be designed with a commitment to family empowerment in mind.

E. Funding--HOW?

Options: legislative appropriation
federal funds (e.g., further use of Medicaid resources, SSBG funds)
private health insurance
private sector resources

F. Evaluation--HOW EFFECTIVE?

Evaluation mechanisms need to be both quantitative (cost effectiveness) and qualitative (quality of services). The process and the outcome of family support should both be examined, both on a systems and a family/individual level.

VI. DEVELOPING A FAMILY SUPPORT AGENDA FOR MASSACHUSETTS

It is an exciting time in Massachusetts; over the past several years interest in addressing these issues and developing a family support system has been growing rapidly. The first statewide conference on family support services took place in November 1986 and brought together 150 parents and professionals to share their experiences and creative ideas for increasing support to families.

An interagency policy group has formed and is distilling the results of that conference into a position paper that will be a blueprint for the development of a family support system in the Commonwealth.

Other groups, the Council included, are continuing to work for program innovations that would support families and are also trying to "spread the word" about what family support is and why it is important.

From these activities, a strong agenda for the Commonwealth is emerging; one that calls for more support to families who provide care at home for family members with disabilities. Working in partnership with them, we can help ensure that these families' lives are infused with dignity and independence, and enable them to live in the mainstream of community life.

If you would like more information on how you can be involved in the family support "movement," call Jo Bower at (617) 727-6374.

P.L. 94-142

Public Law 94.142 is the Education for All Handicapped Children Act of 1975. This section of the PEP starts with a brief overview of some of the rights and responsibilities parents have under this law which is followed by a paper that addresses recreation as a related service within P. L. 94-142. Partnership between parents and school systems is the subject of the next paper and this is followed by a paper that addresses the legal aspects and their implications for the provision of related services. This section concludes with descriptions of several appeals cases that pertain to the provision of related services.

PUBLIC LAW 94-142
AND PARENTAL RIGHTS

by Victoria DeSalvatore

Parental rights and responsibilities are outlined very succinctly in Public Law 94-142. Parental rights focus on access to educational records and information and involvement in the development of educational policy.

1. It is the right of parents to be informed by the local school regarding "identifiable information" of their child. This information is defined as: the name of the child, address, personal identifying information (social security number) and a list of personal characteristics which make it possible to identify the child. Parental rights include knowledge of school policies concerning storage, release and protection of privacy regarding that information. Parents have the right to a description of children on whom information is maintained, how that information is gathered, and potential uses of the information. Parents must be informed of these rights at the initiation of a needs assessment (diagnosis/evaluation).

2. Parents have the right to a full review of the educational records on their child

3. Parents have the right to a full and complete interpretation of the records and any amendments made due to inaccuracies.

4. Parents have the right to permit or refuse release of personally

recognizable information to anyone other than officials of the agency. This right to privacy is upheld by a due process hearing if the parent feels a violation has transpired.

5. Parental rights also include the right to participation in the development and approval of educational policy. These are rights to participation at public hearings and membership in advisory panels. These public policy panels provide opportunities for parents to have a voice in the provision of special services. Overall, parents have the right to decide what educational services will ultimately be provided for their child. Services cannot be implemented without parental consent, and consent can be withheld.

6. Parents have the right to retract their consent at any time. Consent is defined as informed consent with full disclosure of the plan in their native language or mode of communication.

7. Parents have the right to a due process hearing when any of the parental or child rights have suspected violations.

8. It is a parental right and responsibility to be an active member in the IEP (case) hearing. The proceedings cannot begin until the school has the parents cooperation or has documentation detailing the lack of success in methods employed for procuring their cooperation. Having parental input from the planning stage initiates a climate of cooperation between home and school which is considered most beneficial in providing specialized services. The school is responsible to ensure that the hearing or case conference is conducted without the use of technical language so that parents and others can follow and fully participate in the proceedings.

From the outset of referral, there are several responsibilities the school has in regard to parents.:

1. Parents must be informed of the referral.
2. The school may not proceed without consent from the parents to conduct an evaluation.
3. The school must communicate to the parents what their and their child's rights are under P.L. 94-142.
4. The school must notify parents of the IEP Case Hearing and schedule a mutually agreed-upon date and time.
5. The IEP meeting must be conducted in the native language and/ or mode of communication.
6. The school must provide an interpreter if necessary.
7. Upon completion of the IEP process, the school must provide the parents with a written copy of the IEP.
8. Throughout the IEP process, the school must apprise parents of the due process rights of the parent and child.
9. By apprising parents of their rights, the school is meeting their obligation to comply with federal and state regulations to uphold these rights.
10. It is the responsibility of the school to reevaluate the child every three years for appropriateness of placement and services.
11. The school must implement the IEP as it has been written and approved by parents.

When examining rights, roles and responsibilities, it is evident that each of these are clearly delineated by the Law's regulations. It is clear that special education has been written into the educational system for the purpose of serving children and ensuring the best and most approrpiate education.

Appendix

OSERS
NEWS
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Office of Special Education and Rehabilitative Services
U.S. Department of Education ▪ Vol. 1 No. 2 Summer 1986

Clarifying the Standards: Placement in a Least Restrictive Environment

Comments by: Madeleine Will, Assistant Secretary
Office of Special Education and Rehabilitative Services (OSERS)

Some people have interpreted the Least Restrictive Environment (LRE) to mean that all handicapped students would be placed in a regular classroom, regardless of their educational needs, and that a child would have to fail in a regular classroom before special services would be provided. Such is not OSERS' intent.

OSERS' goal is to ensure that:

- Each handicapped child's educational placement is determined annually.
- The placement is based on his or her individual education program (IEP).
- A continuum of alternative placements is available to meet the needs of handicapped children for special education and related services. The continuum includes regular classes, special classes, special schools, home instruction, and instruction in hospitals and institutions.
- Each child is educated in the LRE appropriate to that child.

The overriding principle is that placement decisions must be made on an individual basis and that various alternative placements must be available in order to ensure that each handicapped child receives an education which is appropriate to his or her individual needs.

Findings in the past indicate that placements sometimes are not based on the unique educational needs of the individual child. Placement decisions may have been determined by the availability of space, transportation, or required related services or by the category of handicapping condition.

Therefore, we are reviewing the process by which placement decisions are being made. In order for the LRE requirements to be met, written procedures for placement decisions must be in place. The standards OSERS developed can be used as guidelines to assist states in the development of their own guidelines.

OSERS has received numerous comments and suggestions on the implementation of LRE. We are reviewing these comments carefully and intend to revise our standards to more clearly reflect the intent expressed in this statement. •

RECREATION AND SPECIAL EDUCATION

Gerald S. Fain, Ph.D

When many teachers in our public schools see a special education child, they feel pity. Some feel inadequate. Others feel conflict. Fundamentally, educators as a group, understand and support the concept requiring inclusion of ALL children in regular education regardless of handicapping condition. However, when this mandate is reduced to the individual responsibility of a teacher, some may not be very accepting. This is not to blame teachers for negative attitudes toward children in special education, rather it is to try to understand why they often behave the way they do. I wonder, could it be that even with their education, training, and certification, there are teachers who really do not understand why schools have responsibility for special education?

Personally, I have a much different point of view. When I see a child entering special education, I see a great opportunity. I want to tell my favorite stories about people with disabilities. I am reminded of my friends that, despite disabling conditions ride horses, climb mountains, train for road races, compose music and paint pictures. I am anxious to share these HEALTH GIVING experiences that illustrate how each of us can attain individual freedom and dignity. I see this as a primary responsibility of education. These optimistic feelings of hope are well known to many people who work with children in special education. These are the feelings that make GREAT teachers and recreators. These professionals see more than a handicapping condition and the subsequent need to change their curriculum and methods of instruction... they see children!

INDIVIDUAL ACHIEVEMENT

This point of view or attitude most often comes from personal experience that takes place outside of the school environment. Going to the museum, zoo, or library, spending time at the movies or learning to shoot a basketball are experiences that represent part of normal living. It is during these times that people access AVAILABLE HEALTH and INTACT STRENGTH that may not be revealed through the basic school curriculum. Play and recreation are NORMAL for children. When we get to know children in recreation we have a better chance of seeing them as NORMAL.

The idea of available health and intact strength is fundamental to good education and recreation practice. When we are reminded that most schools are designed to serve the "average" or "norm" we realize that the idea of exceptionality creates a problem. The problem is created when the school steadfastly requires adherance to the principle that, "all children are expected to meet the minimum standards for their respective grade level." If a child gets too far ahead of the norm or falls too far behind, the school is challenged to either fail the child or provide an appropriate curriculum. Thus, regardless as to development of the individual child, the curriculum will primarily be based upon the AVERAGE student. It also implies that if a child has AVAILABLE HEALTH or INTACT STRENGTH in an area that is not of interest to the school, it will not be attended to.

In recreation this need not be the case. The question in recreation ought not be, "what standard have you fallen below?" but rather, "what is it that you CAN DO!" Given your available health and intact strength, how can your individual development be facilitated? This position requires that we accept the idea that HEALTH and STRENGTH are variables which have primary value to the individual; not the norm. The meaning of success or achievement is determined not by the group standards, but by the goals for the individual.

The original rationale for including recreation as a related service within special education was based in part on several assumptions.

1. We understand that ALL children benefit from recreation.

2. We can predict that many of the children placed in special education will be unemployed or underemployed at rates which exceed those of children in regular education.

3. We believe that recreation has curative values that can actually enhance child development and support success in education.

4. We understand that the skills required for successful participation in recreation begin in childhood and last a lifetime.

5. We also understand that recreation behavior is dependent upon effective social skills which are essential to good education.

Moreover, those who have contact with children in special education come to learn that education has meaning well beyond what is written in a report card. Special education is much more than education. It is a moral imperative based in human rights. Children, regardless of their abilities, must be given the chance to develop. This is the one of our most sacred freedoms. Symbolically, this freedom is exercised each time an individual decides what they will do. This is why recreation can be so important: for in recreation, we have the chance to assert our freedom to choose.

DEFINITION OF TERMS

Recreation is included as a related service in PL 94-142. However, the meaning of the word and concept is often misunderstood. This problem is further confounded when we introduce the ideas of therapeutic recreation and leisure.

Recreation and Leisure: Recreation is most often considered to be activity engaged in during discretionary time. It is the qualification of unobligated time that primarily determines recreation, not the activity. Work might be fun at times but work time cannot be recreation. Within this conceptualization of recreation, leisure becomes possible. Leisure is more than freedom to be, it is a state-of-being.

As early as 1918, those in the field of education recognized recreation as an important tool in facilitating LEISURE. At that time, leisure was included among the seven Cardinal Principles of Secondary Education. The other principles included health, home life, learning, citizenship, vocations and character.

During this same period, John Dewey, primary leader in the development of American education wrote,

> "Education has no more serious responsibility than the making of adequate provision for enjoyment of recreative leisure; not only for the sake of immediate health...but for the sake of its lasting effect upon the habit of the mind." (DEMOCRACY AND EDUCATION, p. 205)

Therapeutic Recreation: It has not been until the last decade that therapeutic recreation has taken on meaning within public education. Prior to that time, along with related allied health professions, it was practiced primarily within medical settings.

As a service within special education, therapeutic recreation seeks to contribute to the individual education plan by offering recreation programs that are consistent with the individual needs of the student. The services are usually delivered in a small group or on an individual basis. The purpose of therapeutic recreation is generally seen as contributing to the development of recreation values, interests, and skills. It is because of this rationale, as articulated by educators and parents, that recreation was included within PL 94-142.

CONCLUSION

PL 94-142 asserts, "To assure the free appropriate public education of all handicapped children." Let us be mindful that recreation is a long recognized part of education and it is our obligation to insure that it ought also be free appropriate and available to ALL children.

Toward this end, we may come to understand two important concepts fundamental to both regular education and special education. First, all children benefit from an individualized education plan. The past decade of special education has taught us that virtually all children can be educated. When we individualize the instruction, unique talents are discovered. Imagine how strong American education would be if every child was treated as a special child. This would be an ideal way to serve children. Let us recognize that children have varying needs and abilities which are often neglected in reqular education. Special education has taught us that when recreation is included in individualized instruction, enormous benefit to children is possible.

Second, let us abandon the idea that schools are where education takes place while recreation is left to chance. Education and recreation need not live in two separate worlds. When we dignify recreation by accepting it as part of schooling in America, we allow the legitimate expansion of our curriculum into areas that help reveal the unique abilities of children. The result is that we dignify the child who may not be achieving success in other areas of the curriculum. Not all children ought to be judged by their likelihood to get "good grades," go to college and become tax payers. For some children, learning to live a productive life is entirely dependent upon the ability to participate in recreation and experience leisure.

PARTNERSHIP

THE PARENT/SCHOOL RELATIONSHIP

by

Linda Brouillette

> Special education is now a right to be claimed not a service to be begged... and educators and parents alike must understand their new responsibilities under the law (Liederman, 1975, p. 7).

Since these forceful lines were written in 1975 in the midst of the implementation of Chapter 766 (the comprehensive Massachusetts special education law) parents and educators have been struggling to provide a more enlightened meaning to these rights and responsibilities established by the mandates of law. The task and challenge to both groups has been significant and vitally dependent on the development of a successful school/parent relationship or "partnership." For under both federal and state laws "parents have been made equal partners with the school professionals in the business of educating their children" (Joann, et al., 1980, p. 28).

The purpose of this paper is to assist the parents of children who have special educational needs and the professionals who work with them to develop the confidence and skills necessary to build this crucial partnership. No law , whether state or federal, can legislate partnership. Only people can make real partnership happen. Dedicated professionals, teachers, and parents working together can overcome all the obstacles to providing the "free and appropriate education for all children" that the authors of the federal special education law (modeled after Chapter 766) envisioned.

Unfortunately the development of this "partnership" has been difficult in many instances (Joann, et al., 1980, p. 28). Many parents were disillusioned by the performances of some school districts before the advent of the law and in the early days of Chapter 766 implementation. "Parents often distrusted schools and an adversarial relationship resulted which was detrimental to the child." (Joann, et al., 1980, p. 29). In addition, the adversarial character of an array of published literature for parents (Liederman, 1975; Salett, 1980) fueled these hostilities. For example, Stanley Salett (1980) in a report to Congress quoted a Carnegie Council report The Unexpected Minority: Handicapped Children in America stressing the need for parent involvement in the education of their children and the development of parent self-help groups. But one of the reasons he gives for the establishment of such groups is to gain "greater leverage against professionals and the school system" (Salett, 1980, p. 16).

Given this difficult rocky background school districts have had an awesome task "in regaining the parents' confidence and re-establishing a productive relationship" (Joann, Brown, McGarry, 1980, p. 29). Perhaps, the time has come to shift from an adversarial focus to an informed and cooperative one based on the development of knowledge, skills, and training for both parents and professionals.

Research has documented other problems impeding "partnership" for both schools and parents. For example, the results of one study pointed out that although a parent's right to participate actively in his or her child"s educational planning team was mandated, most professionals felt that parents should only be expected to provide information to the team. "They are not expected to participate actively in making decisions about their child's program" (Yoshida, et al., 1978, p. 534).

A follow-up study to determine how, in fact, parents did feel about their involvement in decision making yielded results similar to the professionals (Lusthaus, et al., 1981, p. 257). Parents did most often find themselves in the role of giving and receiving information. In general this was a role they wished to continue to play. Further, parents only wanted to move beyond the informational role to a decision making role in three areas:1. the kinds of information kept on their children, 2. medical services for their children, 3. the transfer of their children to other schools.

The similarities of feeling in both groups could be viewed at least as a basis for cooperation in the planning process (Lusthaus, et al.,1981 p. 257). Cooperation could then become the foundation for the establishment of a more productive parent school relationship. This cannot be achieved as long as both parents and professionals are relucant to involve each other in more than the traditionally perceived roles that each feels comfortable with. Often the fears of both groups inhibit them from working together in a more give and take fashion. Professionals need to accept parents in more than an informational or subservient role. Parents speaking at a recent conference (TASHE Conference, 1986) emphatically suggested they are often only encouraged to do menial tasks for the school. Substantive roles are discouraged. Overwhelmingly these parents repeated "Give us something important to do and we'll be there." Professionals must be assured that their professional stature will be enhanced, not diminished by providing parents the opportunity to play a greater role in the education of their children. Parents also need reassurance and the confidence to believe that their input in a wider variety of areas regarding the education of their children is vital and equal to that of the professionals because they know their child best. Both parents and professionals need to reach out to each other cognizant of the fears each have.

Other barriers within the educational evaluation process itself that inhibit "partnership" were cited in a 1980 study based on a national survey conducted with 2,500 parents of children with varied disabilities (Salett and Henderson, 1980). In this survey parent response indicated that, although many aspects of the Individualized Educational Plan (IEP) process seemed to be working well, "parents still were not participating as full partners in the development of IEPs " (Salett and Henderson,1980, p. 15). A summary of positive and negative aspects of the process follows:

Positive Aspects
- most parents reported the IEP did contain basic required information
- most parents felt adequately informed about the IEP
- most parents felt the IEP seemed to "fit" their children's needs

Negative Aspects
- most parents felt that they were not being prepared to participate in the process
- parents oftentimes felt IEPs were "canned" or prepared before the meeting
- parents felt IEPs were written using standardized language and jargon

This study demonstrates the progress that has been made by professionals and parents together in the development of the IEP. Much remains to be done, however, to further partnership in the process. Professionals need to be comfortable enough with their roles to let the process truly become participatory. For example, IEP's should be developed in concert with parents, not in stock language prior to meetings. Also, professionals must make every effort to use language that can be understood by everyone involved. Parents need to take responsibility to learn about the process to prepare themselves for more substantive participation.

One other factor relating to partnership in the IEP process was documented by the 1982, _766 Final Implementation Report_ (Joann, et al., 1980). It was found that the entire evaluation process was often traumatic for parents, students, and school personnel alike. Further, with regard to parents

> school staff vastly underestimated the emotional impact of evaluation meetings upon parents. Some parents received a sense from these meetings that the child's disability or need for special education services was in some way their fault. (McGarry, Finan, 1982, p. 59).

Misperceptions such as these certainly have contributed to the building of barriers in the development of school/parent partnerships. Professionals must be cognizant of the common feelings of guilt for their child that parents may feel and relate to them in ways that alleviate these feelings. Professionals should not assume, however, that all families with a disabled child are troubled and in need of help. Most struggle with the same disappointments and are uplifted by the same joys as all other families. Parents, as well, should try to understand the role of professionals more thoroughly so they can try to relate in positive ways.

In addition to these often documented common sources of difficulties impeding "partnership" other kinds of issues are often unrecognized and therefore, remain troublesome. Philip Roos (1984) has identified the following:

1. Values. Frequently professionals and parents assume they hold the same values about what is desirable for their child. In reality those values may be incompatible.
2. Objectives and Priorities. Parents and professionals may have different ideas regarding the relative importance of specific goals and objectives.
3. Long term versus short term orientation. Parents may be more concerned about the present situation with a child than about long term goals. The same could be true of professionals. Goals must be mutually agreeable.
4. Competition. Parents may feel hurt that a stranger (namely the teacher) is more

> successful than they are with the child. The professional may feel threatened that untrained and unsophisticated parents may succeed where they have failed. As a result each may surreptitiously, consciously undermine each other's efforts.

These issues must be recognized and discussed if parents and professionals are to work more cooperatively together.

If the substantive parent /school relationship that improves the quality of student education that the framers of the special education laws envisioned is to be a reality both professionals and parents must continue to reach out to each other and work more effectively together. Each must recognize that respect for the child should be the ultimate band that binds them. Some general recommendations suggested by the research for achieveing this end are presented in the following paragraphs.

The first important consideration is that the law has created real opportunities for professionals and parents to work together to develop more and better program alternatives for children with special educational needs. Parents need not be pitted against professionals to accomplish this. Administrators and educators' attitudes have" clearly changed" in the years since the advent of the special education laws (Joanne, et all, 1980, p. 29). Most professionals have realized that the law provides them with greater opportunities for program alternatives because it presents them with the flexibility and mandate that is needed to develop programs that could only be dreamed of in years past. According to the Chapter 766 Final Implementation Report "this freedom has led to many new successful innovative programs" (Joanne, et al., 1980,p. 28). Parents and professionals in the special education field can and should work together to develop greater resources for the children both groups care about so much.

A second consideration centers on a clearly needed on-going effort to inform parents of their rights under the law and to encourage greater participation in the IEP process. Particularly, greater effort must be made to reach out to "vulnerable multi-problem families" that have so far not participated in the process (McGarry and Finan, 1982, p. 60). Training programs and statements of rights, as well as responsibilities, for both parents and professionals should present information in amicable ways that stress cooperation yet, tenaciousness in the task of the development of appropriate programming for their students. Knowledge of the special education laws and assertive striving in a congenial manner to achieve quality service is the key to successful school/parent partnership.

Specific suggestions to achieving partnership with schools follow in a later section of this paper.

Further, with regard to training programs, if parents and professionals are to be equal partners more training programs must be provided them. The basis of cooperation built upon the role of information sharing that both parents and professionals feel comfortable with must be expanded upon. Training programs that bring both parents and professionals together need to be developed. Many current training programs according to parents are "extremely insulting" (Schulz, 1984). They assume that training is always needed. Many parents have raised children with complicated problems. Both parents and professionals have much to contribute to training programs. Only by pooling resources can they learn from each other. New models of cooperation will be developed as both groups come to see each other as striving for the similar goal of the best education for their children. Then perhaps both parents and professionals can begin to view the parent's role in the educational process as substantive rather than just informational in character.

Successful parent and teacher training programs that do exist must be identified, plans for them disseminated, and they must be replicated. Both groups must make every effort to avail themselves of local programs that are offered and if possible initiate and/or support the development of new ones.

In addition to attending training programs parents must begin to develop self-help groups (Gliedman and Roth, 1980). These groups should be established to provide the support and understanding that only the parents of other children with disabities can provide. Parents who participate in these groups have the opportunity to develop self-confidence and knowledge that can aid them in all facets of their life with their children, including what's best for their child's educational program. If one of the stated goals of the group, however, is to "gain leverage against the school" (Salett, 1980, p. 16) the adversarial character will not only instill negativism in parents but certainly preclude the establishment of cooperative patterns in working with schools. Instead, parents in such groups can do much to work cooperatively with schools. Training programs can be established, speakers can be interchanged, public relations programs for special education programs can be undertaken, the raising of funds of extra program activities can be embarked upon, service on various special education committees can be encouraged, as well as the establishment of a general presence to raise consciousness in the school and community at large. Activities such as these which focus on cooperation and minimize an adversarial role will accomplish much toward the goal of partnership with professionals.

Professionals should be supportive of parents' attempts to start self-help groups. Whenever possible it would behoove them to help initiate such groups. Professionals need to be cognizant of the help that parent groups can provide them in their quest to develop innovative and quality programming for the children they are charged to educate. Cooperation that leads to partnership can make the professional's job easier by providing a broader base of support in the community for the development of programs for children with disabilities.

A third consideration relates to communication and respect. Clear two-way communication is essential to effective parent professional interaction. However, that communication must be coupled with respect. Professionals must accept parents for who they are and parents must do the same.

A final consideration centers on specific procedural suggestions to help alleviate the evaluation trauma that everyone involved in the IEP process feels (Joanne, et al, 1980, p. 29). Professionals must go to every length possible to include parents in all meetings, programs, and the classrooms of their individual children. This means developing an open special education system that invites involvement and scrutiny. Often it means extra office work including phone calls, mailings etc. Meetings should be scheduled at convenient times and places and conducted in a forthright open manner in language understandable to everyone involved.

Parents should make every effort to participate in meetings and programs that are scheduled. If attendence is impossible the school should be notified promptly to enable the program or meeting to go on or be rescheduled. When professionals feel the interest and caring of parents they are motivated even more positively to provide the best education. Oftentimes they are anxious and proud to share success with parents, only to sit in a meeting waiting for someone who does not attend. Partnership is created by everyone's caring and concern expressed through the meeting.

Quality special education cannot "be a service to be begged," but neither can it be just a "right to claimed" or we will be doomed to repeat the mistakes and inadequacies of the past. Instead, quality special education must be forged by a "partnership" based on "responsibilities to be fulfilled" in ever enlightening ways by both parents and educators.

PARENTS AND PARTNERSHIP

Education is a major part of any child's life for many years. It has long been recognized that parent involvement in the process is beneficial for both the child and the school. For your child with disabilities this involvement is crucial. Under the federal special education law known as Chapter 94-142 you have been given the unique right to participate in an equal way with professionals in helping to plan the education of your child. Don't be intimidated by the word "professional!" Some, it is true, still cling to old notions that education for children with disabilities should be separate and decided upon by them. However, most support the intent and rights established by Chapter 94-142 . Most are dedicated people who want the law to work well for all the children they have been trained to serve. Besides, professionals will come and go in your child's school years. Although they may be dedicated and care deeply about your child and his/her education, their involvement is necessarily temporary in nature. With each passing year they must move on to the challenge of incoming children's learning . The life of your child, on the other hand, will be intermixed with yours for a lifetime. You know your child in ways educators can never know. You should, therefore, utilize the right the law has afforded you to play an equal role with the professionals. There are several ways you can begin to prepare yourself to assume a partnership role.

First, learn everything you can about the special education laws. Read as much as you can. A bibliography to get you started is included after this paper. Take advantage of lectures, workshops, and training sessions that are continually being developed and financially supported by private or, local, state, and federal agencies. Many are advertised in local papers, bulletin boards,and radio. Join local support groups and state and national organizations for the families of children with disabilities. These will provide you with a link to other parents with similar concerns. In addition, they will provide you an important source of ongoing new information related to your child's disability as well as the law.

Second, approach your child's school in an assertive, yet positive, friendly way. To get things accomplished will require a combination of these traits. Put your best foot forward, but make your expectations for your child's progress and program clear. In addition, you should make an effort to understand the problems and concerns educators may have. This insight will facilitate the establishment of an amicable, productive relationship. Mutual self-respect is crucial for parents and professionals. You and the professional educators in your child's life need each other. Each possesses a unique perspective and information that make a successful educational program possible.

Third, assumeing a partnership role will require you to have frequent contact, both formal and informal, with your child's school. The following suggestions adapted from the book Partners: A Guide To Working with Schools for Parents of Children with Special Needs by David Lillie and Patricia Place will be of great help in working effectively on an informal basis with the school professionals charged with the education of your child.

1. Try to interact in a positive manner with the people who work with your child. Even though the law stipulates that you should be involved in decisionmaking activities, you may encounter resistance to your inclusion in these various steps. Reacting with anger and bitterness will not help your cause. When you encounter resistance, it is important to stay confident and calm, but insistent.

2. Try to build a good working relationship with your child's teacher. You should have frequent and positive interaction with the teacher to make sure that you know what is going on in the classroom. Share your views about your child's disabilities with the teacher. Ask for advice and suggestions in following through with the school's goals at home.

3. Try to develop a special relationship with one of the school system staff members who demonstrates empathy and understanding of your role as the principal monitor and decision maker for your child.

4. Be your child's service coordinator and recordkeeper. Start a notebook to keep track of names, addresses, phone numbers, dates of visits, and the people present during the meetings. A good technique is to write down the questions you ask at the meetings, the answers you receive, and who gave them to you.

5. Try to keep a record of all correspondence with the school system. It provides you with a way to become an expert on your child's educational program. Record keeping like this may be time-consuming for you, but this time is worthwhile when you consider the impact you will have on your child's future.

6. Become very famlar with the records that the school system is keeping on your child. Ask for copies of your children's records.

7. Be sure you understand the terms used by the school staff members and other professionals. When you don't understand ask for further explanation and an example. Ask questions! It may be that your child's teacher will not bring up concerns because he/she is not only your child's advocate but an employee of the school. A teacher faced with a difficult situation may not volunteer information, but is likely to answer frankly any questions you have the initiative to ask.

8. Think positively. Be assertive in a pleasant way, not agressive in a pushy and angry manner. Examine your own feelings and come to grips with how they relate to your efforts on behalf of your child. Parents of a child with special needs often have feelings of frustration, anger and guilt related to their child 's problem. Relieving this frustration in an angry and hostile mannner may help vent your feelings, but may be destructive in building a partnership with the school that will lead to a good educational program for your child.

Fourth, scheduled formal evaluation team meetings can be a positive chance for the adults most concerned with how your child is doing in school to develop new and satisfying Individualized Educational Plans (IEPs). It is the time for you to express your expectations and concerns as well as give and receive information. Don"t be intimidated by the professionals! Be confident of the value of your contribution to the meeting. Some suggestions included at the end of this paper which were adapted from a book, Communicating with Parents of Exceptional Children by Roger Kroth will be helpful to aid you to fully participate in the process.

Finally, realize that procedural matters can be important avenues to maintaining partnership. For example, try to be on time for appointments. If you cannot attend call the school personnel to inform them as soon as possible. This not only acknowledges your concern for the professionals' time but facilitates the rescheduling of the meeting at a mutually convenient time. In addition, try to respond to notes, calls, and requests from the school as soon as you can. Though it might seem tiring and repetitious someone at school is waiting for your response, perhaps needing something, to work more effectively with your child.

After working with your child's school staff for awhile you will be able to decide whether their attitudes and practices toward your child and other special needs children are indicative of trying to do the best job possible. It isn't easy to meet the mandates of so comprehensive a law. It is difficult work taking much time, energy, and dedication. If you come to feel the school staff is trying their best to provide quality education, continue to work with them often reiterating your expectations and urging them on. If you do come to feel, however, that little is being done, your child's placement is incorrect, or attitudes toward your child are negative you must become more assertive in behalf of your child's education. Speak up and begin to plan a strategy. Talk to the Superintendent and the school committee. Often concerns and differences can be resolved at this level. If this does not expedite needed changes you must prepare to use the due process hearing system established by the law. If it becomes necessary to take such a step it will be adventageous to contact a local advocacy center, Center for Children, or any other such agency, organization, or person concerned with the rights of children. They will be able to provide you with the information and support necessary to see you through this difficult time. You might also find a book entitled Due Process in Special Education On Going to Hearing by Milton Budoff extremely helpful. Remember, during this process your child will remain in his/her current placement. Remember also, that it will be a difficult time for everyone involved - you and your child, as well as the school staff. Don't take the situation personally! But do what you must do for the good of your child while trying to keep a positive, amicable attitude. Your child's feelings about his/her education and the people who are teaching him/her depend upon it.

Suggestions for Active Participation in IEP Meetings

Pre-Conference Suggestions

1. Review records and notes on past conferences.
2. Meet with your child and family to determine questions and information to share.
3. Write down suggestions you have for your child's program.
4. If you feel uneasy invite a friend, another parent, or advocate to go with you to the meeting.
5. Bring any records you think you will need with you.
6. Check on the time of the conference.

Conference Time Suggestions

1. Be on time for the meeting.
2. Introduce yourself and anyone you have brought with you.
3. Be friendly but assertive. Try to put the school staff at ease. Remember, you are here to plan your child's program not to do battle.
4. If a number of people are present, sit in the middle of the group instead of at the end. This indicates you plan to be an active working member of the group and not just the recipient of the plan.
5. Take notes during the meeting.
6. Ask for clarification on anything you do not understand.
7. Ask to see and have copies of any reports or records that are referred to and have them explained to your satisfaction.
8. If the school personnel do not summarize at the end of the conference you should do so. Indicate your understanding of who is to do what for the plan.
9. Sign only papers you are sure you understand clearly. You can sign that you participated in the meeting, but take anything else home to study if you have any questions or haven't had sufficient time to study the plan.

Post-Conference Suggestions

1. Check your notes. Be clear about what you are to do and what the school is supposed to do.
2. Share information and discuss the plan with your child and the family.
3. When the Educational Plan arrives or you have had time to study the one presented to you check it against your notes to ensure it is correct.
4. If everything is correct sign your acceptance of the plan. If it is not call the school as soon as possible to resolve the matter.

5. After the plan is accepted by you and your child work very hard with the school to ensure it success.

Adapted from Communicating with Parents of Exceptional Children: Improving Parent-Teacher Relationships by Roger L. Kroth, 1985.

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The acronym ERIC stands for Educational Resources Information Center. ERIC is a national information system established by the U.S. Office of Education. Its purpose is to collect, process, and make available documents in the field of education. ERIC documents can be obtained from many college and university libraries, including Boston University. Documents are arranged on micro fiche sheets in drawers according to the ED number listed in references. Micro fiche may be taken from the drawer and viewed on a reading machine.

LEGAL ASPECTS AND THEIR IMPLICATIONS FOR THE PROVISION OF "RELATED SERVICES" IN SPECIAL EDUCATION

by Linda Brouillette

Over the past decade tremendous strides have been made to improve programs and services for handicapped students. The Education for All Handicapped Children Act (henceforth called EHCA) and Section 504 of the Rehabilitation Act as well as other regulations and court decisions have provided the impetus for this improvement.

The cornerstone upon which the development of law has rested is that programming must provide "a free appropriate public education" to all handicapped children. According to EHCA, "free appropriate public education" explicitly includes "special education and related services." Special Education is defined as

> specially designed instruction at no cost to parents or guardians to meet the unique needs of a handicapped child including classroom instruction, instruction in physical education, home instruction, and instruction in hospitals and institutions.
> 1401 (16)

Related services are defined as

> transportation, and such developmental, corrective, and other supportive services (including speech pathology and audiology, psychological services, physical and occupational therapy, recreation, and medical and counseling services)... as may be required to assist a handicapped child to benefit from special education.
> 1401 (17)

Although related services can clearly be viewed as part of special education programming according to definition, questions have arisen over the years regarding their provision. Specifically, parents, advocates, and professionals in the field have sought legal precedents to help answer questions such as:

1) When is it necessary to provide a related service?
2) How can related services be most feasibly utilized for the benefit of handicapped students?

As the result, litigation has arisen concerning the provision of these services. Much of it has been concerned with defining the parameters of the specific related services defined in the regulations. The rest has been concerned with whether or not certain services should be considered related services under the law. Issues that have been litigated so far include the provision of counseling, parent counseling and training, health related services, transportation services, specialized environments, and recreation programs (Osborn, 1984, p. 249).

The Supreme Court, itself, has now addressed these questions by the promulgation of two recent decisions. Both seem to have far-reaching implications to the provision of all types of related services to handicapped students.

Two lower court decisions were overturned in the case of The Board of Education v. Rowley in its ruling that the provision of a sign language interpreter for a deaf child was not necessary under the tenets of the law.

Amy Rowley was an eight year old deaf child who was making above average progress in the regular classroom as evidenced by passing grades. She had an IEP in Kindergarten which included several accommodations by the school to her handicap (i.e., FM hearing and sign language course by school personnel, TTY machine at school to communicate with Amy's deaf parents). Her IEP for first grade called for 3 hours each week of speech therapy and one hour a day of instruction from a tutor for the deaf. Respondents in the case felt this was insufficient service, notwithstanding Amy's regular class progress, because she had been raised in a total communication approach. She was only able to understand 59% of what was spoken in class where total communication was not used.

The court felt that since Amy was receiving substantial specialized instruction and related services at public expense and making progress with such a program she was receiving an "appropriate education" without the interpreter.

The Justices based their decision on the key issue of how to define the meaning and determine the scope of a "free appropriate public education." In so doing, the court rejected the contention that "appropriate" means providing equal educational opportunity, noting that the opportunities offered to students vary "depending upon a myriad of factors that might affect a particular student's ability to assimilate information" (Board of Education v. Rowley, 1982, p. 3047).

Further, the court stated that "the Act imposes no clear obligation upon recipient states beyond the requirement that handicapped children receive some form of specialized instruction" (Board of Education v. Rowley, 1982, p. 3043). There is no requirement that services provided be sufficient to maximize each child's potential. If, in fact, personalized instruction is being provided with sufficient supportive services to permit the child to benefit from the instruction, the child is receiving a "free appropriate public education" as defined. It can clearly be seen that the entrustment of the handicapped child's education and related services is placed in the hands of individual states once procedural requirements have been met (daSilva, 1982, p. 241).

The court also argued that handicapped students are not entitled to a specific level of education but, "that the intent of the Act was more to open the door of public education to handicapped children in appropriate terms than to guarantee any particular level of education once inside" (Board of Education v. Rowley, 1982, p. 3043).

Another recent court decision, however, contrasts the possible setbacks in the provision of related services that the Rowley decision portents. On July 5, 1984, the court not only affirmed the constitutionality of PL 94-142 but convincingly acknowledged the provision of related services under the law. In the case of Irving School District v. Tatro the Court found that "the court of appeals was clearly correct in holding that CIC (Clean Intermittant Catheterization) is a supportive service. . . required to assist a handicapped child to benefit from special education" (Irving Independent School District v. Tatro, 1984, p. 3372).

Amber Tatro was an eight year old girl born with a defect known as spina bifida. As a result she suffered various orthopedic and speech impairments and a neurogenic bladder which prevented her from emptying her bladder voluntarily. Consequently, she needed to be catheterized every three or four hours to prevent injury to her kidneys. According to accepted medical practice a procedure known as clean intermittent catheterization was prescribed. This is a simple procedure that can be performed in a few minutes by a lay person with less than an hour's training. The school district Amber was attending refused to perform the procedure during the course of the school day on the grounds that "medical services" could qualify as a related service only when they served the purpose of diagnosis or evaluation. In its opinion the court clarified that CIC is not a "medical service" (i.e. one that must be performed by a physician) but a "school health service" which is included in the related services listed by the law. The court referred to the Rowley decision when it stated

> As we stated before, Congress sought primarily to make public education available to handicapped children and to make such access meaningful (Irving Independent School District v. Tatro, 1984, p. 3377).

Further the court in the Tatro decision declared that:

> A service that enables a handicapped child to remain at school during the day is an important means of providing the child with the meaningful access to education that Congress envisioned . . . Services like CIC that permit a child to remain at school during the day are no less related to the effort to educate than are services that enable a child to reach, enter or exit the school (Irving Independent School District v. Tatro, 1984, p. 3377).

It seems the Rowley and Tatro decisions provide some direction in determining when a student is to receive a related service; however, many ambiguities still remain. Although the basic tenets of EHCA were endorsed, "the court restricted its holding to procedural rights and emphasized that Congress did not impose substantive standards on states regarding the components of an appropriate education" (McCarthy, 1983).

Thus, the entrustment of the handicapped child's education and related services is placed in the hands of individual states.

It will, then, be the task of advocates and professionals providing services to the handicapped to demonstrate on a case-by-case basis that the service is needed to provide the child with the opportunity to "meaningful access" and "some educational benefit." Since the court did not define either phrase, except as it related to Amy Rowley, the outcome of each case will depend upon the degree to which "related service is seen as providing access to or ensuring some educational benefit."

Other factors that professionals and advocates can point out to enhance cases dealing with the provision of related services are outlined as follows:

1) Clearly state the facts of each case and differentiate it from the facts of the Rowley case (Amy was in a regular class, she had no mobility problems, etc.) (Meador, 1983).
2) The court in the Rowley decision stressed the requirement of parental involvement in the education of each handicapped child. If a parent disagrees with the school that the child is "benefiting" from the services provided by the IEP, he must be aware and knowledgeable to pursue further or alternate services under the law. Professionals and advocates must aid parents in developing parent awareness.
3) Although the Rowley decision precluded "maximizing potential of students" as a standard for judging services, at the least a school district must provide the services "needed to enable

children to achieve a reasonable degree of self-sufficiency" as the Congress intended in PL 92-142 (Meador, 1983).

4) The Tatro decision clearly establishes a reaffirmation of related services in spite of the ambiguity of the Rowley ruling. Professionals and advocates must show precedent from Tatro and other appropriate state cases to establish the need for related services, for the court in Tatro clearly stated that

> Congress plainly required schools to hire various trained personnel to help handicapped children such as "trained occupational therapists, speech therapists, psychologists, social workers, and other appropriately trained personnel (Irving Independent School District v. Tatro, 1984, p. 3378).

The provision of "related services" in the immediate future it seems, might depend upon the ability of concerned parties to state their case to local school districts. Hopefully, this will build needed precedents for provisions of services. The Supreme Court decisions also portend that some types of related services will be easier to justify than others. Unquestionably, services that can be administered by a school nurse will be accepted as set forth in Tatro. Services that enable a child to physically enter or exit school as was also specifically referred to can be readily accepted as needed "related services." The key issue to expand this narrow interpretation rests on the Tatro phrase that services needed "are services that are related to the effort to provide benefit from special education."

At this juncture it seems appropriate to review areas of the related services provision litigated as listed earlier in this paper in relation to the Supreme Court decisions discussed. Health related services certainly would be classified as related services in light of the Tatro decision as long as those services need not be provided by a licensed physician. Transportation and Specialized Environment issues are also more clearly explained by Tatro's statements regarding the clear-cut intention of Congress to provide services so that handicapped children could have "meaningful access to education" (Tatro, p. 3377). As the court pointed out, a service enabling a handicapped child to remain at school as well as to reach, enter, or exit the school, is mandated under the related service provision of the law.

Counseling, psychological and social work services, as well, are also clearly required under EHCA (Osborne, 1984, p. 250), and should be provided a child when those services are required to help him benefit from special education and the service is contained in the child's IEP. Once again, Tatro's attempts to clarify services that could and "benefit" is important to consider. Although counseling is generally regarded as a related service if the child demonstrates need, psychotherapy as a form of counseling may or may not be required. This depends on state law which designates whether only licensed physicians or, in fact, other trained professionals can provide the service. If only a licensed physician can provide the service, it is considered a medical service. As discussed earlier such services are excluded from the related service's provision except for evaluation or diagnostic purposes.

The precedent for parent training and counseling has also been established by the case of Stacey v. Pasadena Independent School District (1982). Since many severely handicapped children require consistency of approach between home and school to benefit from education, the court in this case ordered that the school must provide training in behavioral techniques to manage the child's behavior and counseling to help reduce the emotional stress of the burdensome demands placed on them by their child's disability.

Finally, although recreation was not specifically referred to by the Supreme Court, its provision as a related service has been applied to "educational benefit" in several appeals and precedent setting court decisions. These cases, although heard in accordance with existing local and state statues, point out the direction future cases must take to expand the motion of all types of related services.

The case of Sandra T. (BSEA #3231), a fourteen year old student with Down's Syndrome, illustrates several issues in related services provision. Although both parties in the dispute (parents and school) agreed that Sandra's disability caused developmental delays, health and socialization problems, and language delays, the public school staff felt it could provide for her needs within its regular physical education and after-school extracurricular program. Sandra's parents contended that the school had failed to implement provision of a past IEP calling for a six-hour, after-school social/recreational program, and further, the school had failed to insure access to and equal opportunity to participate in its extracurricular activities which are offered to students without handicaps.

During the exposition of the facts in the case, several expert witnesses testified as to the importance and need of recreational programming for Sandra. Dr. Gerald Fain, a Professor in Leisure

Studies at Boston University testified:

> "Therapeutic recreation could employ the activities of sport, but the goals of instruction would be directed . . . to the use of discretionary time in a beneficial way (Sandra T., 1980, p. 6)."

When asked about the educational necessity of such a program for Sandra, Dr. Fain stated that:

> "The development of skills essential to independent functioning in adulthood has been a fundamental tenent of public education. If Sandra is unable to use her discretionary time effectively . . . then education has failed her (Sandra T., 1980, p. 6)."

The hearing officer in his decision in the case found that the school had failed to, and would forthwith be required to, provide the after-school recreation program for Sandra as outlined by a prior IEP. In addition, the school had failed to insure access and equal opportunity to participate in its regular extracurricular activity program and would be required to

> examine its extracurricular programming and analyze the extent to which Sandra could participate in whole, or in part, in such activities, and if necessary for her participation, provide for modifications (Sandra T., 1980, p. 12).

He based his findings on several key points. First, he cited two regulations taken from a new requirement in Section 504 which specify that "handicapped children must also be provided non-academic services in as integrated a setting as possible." Also the school shall "provide non-academic and extracurricular services in such manner as is necessary to afford handicapped students an equal opportunity for participation in such services and activities (Sandra T., 1980, p. 12). Second, the hearing officer found Dr. Fain's definition of education as a means to assist an individual to function independently as an adult to be appropriate. For Sandra, this must include the need for special education and related services that "encompass a broad range of tangible experiences involving socialization, recreation, occupational, academic and survival skills" (Sandra T., 1980, p. 7). Third, the hearing officer rejected a confining definition of related services offered by a school official as being "more restrictive than law and regulation provide." Fourth, the officer noted that planning for the academic and counseling function was adequate, however, planning for extracurricular, non-academic programs was not addressed. This decision illustrates the importance placed on recreation and extracurricular activity when interpretation of the law is required.

In the case of Birmingham School District v. Brian the parent of a handicapped child who had been in a summer program for four years requested due process when her child was denied access, the fifth time, based on school financial considerations.

The facts in the case were undisputed. Brian is a fourteen year old autistic child who had been enrolled in the school's program for children with severe behavior and language disorders. The program emphasized heavily structured training socialization, behavior modification, and cognitive learning. For 4 years prior to 1979 the program included a summer session funded by the federal government. When funding was lost and alternative funding sought from the school district was denied, the program was discontinued. Brian's mother then requested a hearing seeking a decision directing the continuation of the program.

The local hearing officer held a series of administrative hearings to determine whether the summer program was necessary in order for Brian to obtain an "appropriate" education. The hearing officer concluded from the testimony, almost without exception, including witnesses called by the school district, that some summer program or service was needed to meet Brian's needs.

The defendants appealed the decision to the courts on two grounds. First, the school argued that special educational statues and regulations clearly state that "school districts should be required to provide only programs which are primarily of an instructional nature and not conduct what is essentially a social services program (Birmingham and Lamphere School Districts v. Brian, 1982, as cited in EHLR, 1983, p. 554:320). Second, the law requires only a 180 day program for education and the summer program surpasses this requirement, therefore, is not necessary to provide.

The circuit court upheld the hearing officer's findings regarding the necessity of conducting a summer program for Brian. It found there was

> no reason to question the local hearing officer's conclusion that the proposed summer enrichment activities (camping, field trips, swimming, playground and recreational activities) fall within the broad definition of "special education" and "related services" (Birmingham School District v. Brian, 1982 as cited in EHLR, 1983, p. 554:321).

It might be noted, and the court pointed out, that the term "related services" specifically includes supportive services such as recreation.

From the discussion of the foregoing cases it can be seen that the precedent for provision of recreation as a "related service" in special education has been established.

Sandra T's case was successful because it presented several key points that might be helpful to the development of other cases and broader utilization. Several times through testimony in the case the word "benefit" or "beneficial" was used by expert witnesses to describe the proper role of education for Sandra. Since the law requires what is needed to assist a child to "benefit from special education" the use of this terminology is important to a judicial acceptance of the need for recreation being presented. Since it has been shown that neither the Rowley or Tatro decisions defined what "educational benefit" means or how it might be measured, professionals should begin to examine the need for building a more expansive definition than what might be implied by the courts and the public. Second, Dr. Fain's testimony describing the goal of "independent functioning in adulthood" is timely since it begins to provide the definition of "benefit" that can be most helpful.

The decision in Sandra T. is a helpful one, particularly for professionals providing service to handicapped children in Massachusetts. Since the wording of Chapter 766, the Massachusetts State Law concerning handicapped children, provides a higher standard than federal law the provision of "related services" can be more readily established. Section 2 of the Massachusetts law (Chapter 766) does make reference to "maximizing development" and reassignment to other programs if they can be shown to be "more beneficial" for the student. This is an important concept since it strengthens the mandate of schools in Massachusetts to provide more and higher quality services than EHCA provides for.

Brian's case is significant because recreation as it applied to

Brian's specific need was demonstrated to be as important as academic instruction. Another significant issue that Brian's case points out is the notion that education for the handicapped requires only a 180 day program. In Brian's case the court clearly stated that the 180 day requirement is a minimum provision for instructional days. As precedent the court cited two related cases.

Armstrong v. Kline (1979) was a case that established the principle that "for certain handicapped children a program in excess of 180 days is required if they are to attain that level of self-sufficiency that is otherwise possible given an appropriate education" (Armstrong v. Kline, 1979, p. 605). [See Appendix for a case summary.]

Georgia Association of Retarded Citizen v. McDaniel (1981) was a second case that raised the similar issue of the 180 day instructional rule. The court found a limit of 180 days of instruction did violate EHCA as well as Section 504 of the Rehabilitation Act. Further, in its decision, the court reiterated the strong claim for the need of related services for certain disabled students. The court definitively stated that

> some special treatment may be necessary for handicapped children to benefit from theirs (education). If a child needed a special service to gain equal benefit from his education, the denial of that service would constitute discrimination in violation of Section 504. Individual attention to the needs of each handicapped child is the only way to determine whether such special or additional services are needed (Georgia Association of Retarded Citizens v. McDaniel, 1981, p. 1280). [See Appendix for case summary.]

If this provision of recreation as well as other services is to become more established as a need for handicapped children to benefit educationally, professionals must initiate action in several areas:

1) As can be seen from the discussion of the issues in Brian's case, the efficacy of extended year, plus after-school programs must be studied. To date research has not been able to "provide clear justification for them or guidance as to eligibility criteria and type of programming" (Kubler, 1983). Evidence is lacking and research is needed to demonstrate that summer or after-school programming is effective in eliminating regression and permitting handicapped students to thereby benefit from special education.
2) Educators and professionals must now develop creative innovative ways of providing related services to schools that are burdened with financial as well as time factors in their provision (Exceptional Parent editorial, August 1984).
3) When schools in the past have attempted to provide service they oftentimes compete with social agencies delivering the same type service. Attempts at the local level to work cooperatively with other agencies must be supported.
4) Parents must be aided to become more aware of their rights in relation to the provision of related services, so they can press cases of individual need to their school districts. Further, litigation in individual cases must be pressed in the courts to expand the ambiguous parameters of the related service provision of the law.

In these days of conservatism in government, and judicial and financial restraint, it is imperative that everyone committed to the best education for handicapped students come together to preserve the strides that have been made and move forward to improvement. The provision of "related services" should be a major way to forge that improvement.

APPENDIX

Georgia Association of Retarded Citizens v. McDaniel

This was a class action suit brought to Atlanta, Georgia District Court on April 3, 1981. It was initiated around the central issue of whether Russell Carrie, a profoundly mentally retarded boy and others, members of the class he represents, are entitled to be considered for or to receive more than 180 days of free public education under EHCA.

The exposition of the facts in the case first included a background discussion of mental retardation. Next, a review of local and state policy regarding the provision of an extended year program was undertaken by the court. Another important aspect related to the effects of breaks in programming on the educational achievement of mentally retarded children. Much testimony was presented to illustrate the contention by plaintiffs of the damaging effects of summer programming breaks as well as much by defendants denying the claim of regression over the summer.

The decision of the court documented several key points. First, the court clearly established through a lengthy discussion the emphasis EHCA places on meeting the "unique needs of a handicapped child (EHCA, 20 U.S.C. 1401 /16/)." By tracing the main definitions and provisions of the law through the lens of an individualizing perspective, the court sought to build the case for its second key point. In light of EHCA's clear emphasis on the individual needs of each child the court determined that

> an across the board policy prohibiting the consideration of a child's needs beyond 180 days violates the Handicapped Act as does the policy limiting the provision of schooling to 180 days . . . Such a policy assumes that no child needs more than 180 days, without any individual consideration . . . There can be no question that the defendents must provide schooling in excess of 180 days for any child that may need it (p. 1278).

In spite of the fact that school and state officials testified that there was no policy against the provision of more than 180 days of services if a child's IEP called for it, the court found that officials did, in fact, refuse to consider such a program.

Further, the court found that the denial of more than 180 days of education for disabled students without regard to need, also violated Section 504 of the Rehabilitation Act which prohibits a disabled individual from being denied the benefits of an educational program which receives federal financial assistance.

> It (Section 504) indicates that special treatment or additional services may be necessary for the handicapped person to fully enjoy the benefits of his education (p. 1280).

If the student needs more than 180 days of education yearly to "fully enjoy the benefits of his education," then the school must provide what is needed.

APPENDIX

Armstrong v. Kline

This is a class action suit which was initiated around the issue of whether the class certified is entitled to more than 180 days of free public education.

In January 1978, five handicapped children and their parents commenced three class action suits which were consolidated and certified as a class in a civil case (Armstrong v. Kline, No. 78-172) on February 21, 1979. A suit was then brought to District Court on behalf of a class composed of

> All handicapped school aged persons in the Commonwealth of Pennsylvania who require or who may require a program of special education and related services in excess of 180 days per year and the parents or guardians of such persons (Armstrong v. Kline, 1979, p. 586).

The exposition of the facts in the case included an in-depth analysis of the characteristics and needs of the children of the class, the educational process for them, and the effects breaks in programming would have on their progress.

Generally the court recognized two separate categories in the class -- the severely and profoundly impaired by mental retardation and the severely emotionally disturbed. Each of these groups was described and examples of children in the suit were used to illustrate each category.

The court first determined that educational goals for each group are developed to help each child attain the highest level of self-sufficiency possible. This may include self-help skills, avoiding institutionalization or attaining a level of independence which would enable the student to live in a group home or in a family home and work in a sheltered workshop.

The educational program, then, is developed based on the needs of the child. This may include such things as toilet training, dressing, personal hygiene, etc. At times it may also include psycotherapy or counseling that is designed to help the person cope with the disturbance that may be a source of the problem. The court also clearly stated into its factors that affect learning section that

> The opportunity to practice outside the formal classroom is a significant factor in learning and the length of time that a child has to practice a skill increases the likelihood that the skill will be mastered (p. 592).

With regard to whether breaks in programming would cause regression in the class the court concluded that

> because they have a problem remembering what they have learned, even a behavior which has been mastered must frequently be repeated or it will be lost. Breaks in programming, of course, means that the opportunity to practice skills with qualified teachers, which is crucial to both learning and retention, decreases and therefore the chances that the child will regress increases (p. 595).

Further, the court found that the rate of relearning what has been lost is different from child to child. Some children may experience neither regression nor long periods of time to regain skills, but the evidence convinced the court that some children experience both, due in part to the very nature of their disability.

In its decision the court through a discussion of EHCA legislative history concluded that "Congress recognized attaining self-sufficiency as a goal of an appropriate education for handicapped children (p. 604)." Therefore, the unique needs that must be met by the educational program" include those that, if satisfied, allow the child, within the limits of his or her handicap, to become self-sufficient (p. 604)." Finally, as the court found earlier, for certain disabled children a program in excess of 180 days is required if they are to attain the level of self-sufficiency so often referred to by Congress. Therefore, the 180 day rule is not applicable to the children of the class.

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Sandra T. BSEA #3231 (Massachusetts 1980).

Stacey G. v. Pasadena, 547 F. Supp. 61 (1982).

The Exceptional Parent, editorial, 1984, 14 (5), p. 2.

Appeals Cases

EDITOR'S NOTE

If a parent is unsatisfied with the Individual Educational Plan and chooses to reject the plan, (s)he has the right to appeal the decision of the local school system. There are several steps in the appeals process:

1. The parent initiates the process by returning the signed Educational Plan, and by checking off the box stating, "I DO NOT APPROVE." A parent can also start the appeals process by writing directly to the Bureau of Special Education Appeals (BSEA).
2. Whenever there is a difference of opinion over an IEP, every effort is made to settle the problem in an informal discussion. While every effort is made to reach agreement, arrangements are made for formal appeals procedures in the event that informal discussion does not solve the dispute.
3. Within 5 days after the rejection of the IEP by the parent, the school sends copies of the rejected plan and assessments of the child to the Bureau of Special Education Appeals. The BSEA is an office within the State Division of Special Education where any parent or student]8 years of age or older may appeal a disputed Educational Plan.

On the following pages, the reader will find a number of cases brought before various local or regional BSEA's in the form of formal hearings. These and other cases are included in one of Schole's electronic databases. (See PEP section on telecommunications.)

BSEA #3231   JUNE 7, 1980
SANDRA T.

PRELIMINARY STATEMENT - Sandra T. is a 14 year-old student with Down's Syndrome resulting in global developmental delays. For six years she attended the Cardinal Cushing School as a residential student. This placement had been extended one more year as the result of a prior appeal. Therefore, Sandra was enrolled in the public school at the end of this time pursuant to an IEP amended by a mediated agreement. This agreement included assignment to a substantially separate class, as well as six hours per week of after school social and recreational programming supervised by a teacher aide. Parents felt the agreement was not adhered to over the next years of the plan and their daughter had been denied access to regular education extracurricular activities.

ISSUES: Whether the IEP of that year and the subsequent year is adequate and appropriate to meet Sandra's special needs in relation to recreational, extracurricular activities and leisure skill provisions. Do Sandra's special needs indicate that an after school therapeutic recreation/leisure education component be included in her IEP?

Were there provisions for access to, and equal opportunity to participate in extracurricular activities after school hours which are offered to students without handicaps? Such provisions may entail appropriate modifications of existing programs and/or the development of new appropriate services and activities.

Did the school district fail to comply with the mediated agreement and modification of the IEP for Sandra T.?

FINDINGS: The amended IEP and the subsequent one are inadequate for failing to furnish adequate recreational and leisure skill services during after school hours. Sandra does need such a program.

The School district failed to implement provision of Sandra's IEP for a six hour after school social/recreational program during the school years in question. Such a program must be initiated as the plans stipulated. Further, a therapeutic recreation specialist shall provide an in-service program for an hour a week for fifteen weeks to interested parties, parents, teachers, and the teacher-aide designated to work with Sandra.

The school district failed to insure access to and equal opportunity to participate in extracurricular activities which are offered to students without handicaps. Therefore, then newly instituted program must include activities available to non-handicapped students with modification and support as needed for Sandra to participate.

BSEA #3366 JANUARY, 1981
JAMES G.

PRELIMINARY STATEMENT - James is a seventh grade student who has specific learning disabilities with below-grade level skills in math computations, and poor peer relationships. He has a preoccupation with fantasy, has difficulty adjusting to new situations, exhibits much anxiety, and evidences many psychosomatic episodes. IEP includes two sessions weekly in the Resource Center in accordance with a 502.2 prototype. The plan failed, however, to provide for an emotional component even through the boy was receiving psychiatric counseling once a week and an assessment by this doctor was made available to the team.

ISSUES - Whether the proposed IEP is adequate and appropriate to meet James' needs without the inclusion of an emotional/psychiatric component.

FINDINGS - The IEP was inadequate to meet James' needs since it failed to provide for his continuing emotional problems. Psychotherapy services were to be added to the IEP and paid for by the school. Reimbursement for past therapy is to be given to parents.

BSEA #3592 APRIL 13, 1981
MITCHELL F.

PRELIMINARY STATEMENT - Mitchell is a 16 year-old boy with learning disabilities in the area of written language. He exhibits excessive distractability and emotional problems including low self-esteem, serious identity issues and family problems. This culminated in a severe emotional crisis resulting in a failure situation in school and severe problems at home.

ISSUES - Is the IEP adequate and appropriate for Mitchell? (Prior to the hearing the parties agreed to a plan which includes the following provisions.)

FINDINGS - There will be a continuation of psychotherapy for Mitchell and his family which will become part of his educational plan. Also group counselling will be available in the school. A psychologist will be available in the school setting in the event of school time emotional problem. Mitchell will, in addition, receive one-to-one tutoring in English and individulized small group instruction in Social Studies as previously offered by the school the year before.

BSEA #3683 JUNE 10, 1981
BRANDY R.

PRELIMINARY STATEMENT - Brandy is an eight year old youngster who evidenced visual and gross motor problems in Kindergarten and first grade even with corrective lenses. Evaluation findings indicated weaknesses in reading, arithmatic handwriting, visual perceptual, motor areas, and body image.

ISSUES - Whether the IEP was adequate and appropriate to meet Brandy's needs for the current year.

Whether the school is financially responsible for services provided at Children's Perceptual Achievement Center and transportation costs thereto. In addition, should parents be reimbursed for costs of an independent evaluation.

Whether Brandy's special needs required remedial services during the summer.

FINDINGS - The hearing officer found the plan adequate and appropriate. Services shall not be reimbursable. The costs of the evaluation will be reimbursed because the team considered the findings and utilized them.

The third issue need not be discussed in light of findings on the other two.

BSEA #3764 FEBRUARY 12, 1981
CHRISTINE F.

PRELIMINARY STATEMENT - Christine is a sixteen and a half year old girl who has cerebral palsy, a seizure disorder, and is mentally retarded, currently in a 502.4 program.

ISSUES - Disputed is whether Chrissy needs more programming in addition to that of her existing program. Also, whether past-education decision made by the town violate Section 504 of the Rehabilitation Act of 1973 and necessitate compensatory remedies. Should the proposed IEP include

1) additional occuptional therapy
2) additional individual assistance
3) an after-school recreation program
4) peer group counseling to address issues of sexuality
5) a summer day or residential program

FINDINGS - 1) Christine's occupational therapy needs can be adequately met within the school program. Others besides the assigned therapists coordinate efforts to work on skills.

2) Christine's need for individual assistance can be adequately met within the program. No evidence presented that Chrissy was not progressing in her regular program. Teachers expressed the contrary and evidenced understanding of Christine's needs.

3) To adequately meet Christine's educational needs, the IEP should include after-school recreational program. However, she is not in need of therapeutic recreation services. The school has reponsibility to open extra-curricular activities in the school and/or develop new programs to meet handicapped students' needs. School must provide a list of after-school programs appropriate and available to Christine.

In spite of testimony for therapeutic recreation, the officer found that for Christine it was not a related service required to enable her to benefit from Special Education for 2 reasons: First, there was testimony that Chris did not know what to do to have fun, however, it was also stated that in an unfamiliar gym she immediately went over to a basketball and shot baskets.

Second, there was testimony that there was a need to develop cooperative play skills with peers, however, the test for determining this was held in an empty gym. The officer found that the therapeutic recreation program did not substantially differ form adaptive physical education.

4) Christine's educational needs can be adequate and appropriate met within the 180 school year. The town provided extensive evidence that Christine would not regress over the summer, as evidenced by teachers who testified that it had not taken her long to regain skills.

BSEA #4004 APRIL 16, 1981
KAREN H.

PRELIMINARY STATEMENT - Karen H. is a 20 year-old moderately retarded woman exhibiting severe speech and language problems (a diagnosis of "elective mutism" had previously been made).

ISSUES - The issues of the case are:

1) Should the school committee be considered in noncompliance of Chapter 766 because it failed to implement the recommendation for a full-time aide as contained in the Additional Information of the IEP of 1980?

2) Is the IEP proposed for 1981-82 adequate to meet Karen's special needs?

3) Is Karen entitled to compensatory services (in the form of extending her entitlement to 766 services beyond her twenty-second birthday) as result of failure to furnish her an aide?

4) Should the treatment regime focus exclusively in development of oral language as recommended by CHMC (Children's Hosptial Medical Center)?

FINDINGS - The findings of the case are that the IEP must be rewritten to incorporate the treatment regime of CHMC. Also, an aide must be furnished forthwith. Finally, Karen is entitled to compensatory services in the form of extension of salutatory entitlement.

BSEA #4289 JUNE 15, 1981
JASON A.

PRELIMINARY STATEMENT - Jason, age 9, has been diagnosed as a child with non-progressive arthrogyposis involving the upper extremities. This handicap results in stiffness of joints, extreme muscular weakness and imposes limitations on the use of shoulder, elbow, wrist, and fingers.

ISSUES - Pursuant to the last accepted IEP, is the school committee obliged to make payment for occupational therapy services furnished Jason?

Is the current IEP adequate and appropriate to meet the special educational needs of Jason?

Parents understood all expenses were to be paid. School felt only transportation because the services were needed for medical not educational reasons.

FINDINGS - The school committee is obliged to pay of occupational therapy costs retroactive to the beginning of IEP. It is not just necessary for medical but educational reasons as well.

The new educational plan must include continued therapy. It is needed because Jason's current ability to function inregular education is attributable to and, in fact, contingent upon on-going therapy.

BSEA #4313 APRIL 30, 1981
GEORGE D.

PRELIMINARY STATEMENT - George D. is a 7th grade student who has, according to testimony, "significant peer interaction problems and a fear of adolescence." He lacks socialization skills, has confusion about boundaries, is unable to make independent decisions and is anxious, disorganized and fearful.

ISSUES - 1) Is George's current classroom placement for his 1980-81 IEP the least restrictive adequate and appropriate setting in which to address his special education needs?

2) Are the counselling services offered in George's 1980-81 IEP adequate and appropriate to meet his special education needs?

3) Is the school committee financially responsible for George's individual therapy with a private therapist?

FINDINGS - George's placement in the self-contained social adjustment class is the least restrictive adequate appropriate setting for George. Also, in-school individual therapy should be offered by the school so the IEP was inadequate for not doing so. Finally, the school committee is financially responsible for the individual therapy for George. It should be noted however, that the school committee could in the future provide adequate in-school services if a weekly, 50-minute session with a qualified therapist could be provided.

BSEA #4401 JUNE 3, 1981
ALICIA M.

PRELIMINARY STATEMENT - Alicia is a severely retarded 11 year-old girl who requires nearly total care. She is myopic, has a severe gross motor delay, relies on walker for movement, is not toilet trained, and recently diagnosed as having a severe hearing loss for speech range.

ISSUES - 1) Is the transportation provided to Alicia persuant to her IEP adequate and appropriate and safe? Does she need a monitor on the bus?

2) Must quarterly reports be sent to Alicia's parents?

3) Are adaptive physical education and an after-school recreation component necessary to an adequate and appropriate IEP for Alicia?

4) Would Alicia regress without a twelve-month educational program as part of her IEP?

FINDINGS - The transportation currently being provided for Alicia is adequate and appropriate. Alicia does not need a monitor as there are several other people on the bus. Quarterly reports were required until July 1, 1981. Now reports must be issued semiannually. On the issue of adaptive physical education and recreation, the school committee is required to have Alicia evaluated by a qualified specialist and if such services are required, they must be incorportated into her next plan. Finally, Alicia does need a twelve-month plan to prevent regression and the school committee must find an appropriate one. It is not the responsibility of the parents.

BSEA #4900 AUGUST 24, 1981
ARI R.

PRELIMINARY STATEMENT - Ari is a three year old boy with cerebral palsy of the left hemiparesis. He has received weekly physical therapy since he was 8 months old and occupational therapy since he was 18 months old. The public school developed an IEP calling for one session/week each of occupational and physical therapy and weekly consultations. In addition speech therapist would monitor Ari's speech every three months.

ISSUES - Parents rejected the IEP because:

1) The town offered standard occupational and physical therapists who lacked the additional neurodevelopmental treatment certification.

2) The occupational therapy was not provided on a 12-month basis.

3) IEP specified no goals or objectives.

FINDINGS - The town provision of a standard physical and occupational therapist is adequate and appropriate. The hearings officer based his decision on the fact that both types of therapists work on similar goals. However, the town should modify their IEP to provide the services for a 12-month period and to include the goals and objectives recommended by the therapists involved.

BSEA #4949 JANUARY 11, 1982
TARA K.

PRELIMINARY STATEMENT - Tara K. is a 7 year-old girl who is a second grader who attends parochial school. She presently receives no special education services from the public schools, although she does attend remedial reading classes at the parochial school. Tara has had various problems including fine motor control with a short attention span. She was retained in first grade. She had a CORE evaluation at which it was recommended that she be provided daily 30 minute learning disability tutoring sessions. Tara's progress is still quite limited. Parents have rejected new IEP becuase they feel Tara needs cognitive control therapy which the plan does not provide.

ISSUES - Should the school committee be required to provide Cognitive Control Therapy?

FINDINGS - Cognitive Control Therapy is an essential element of Tara's program and the school district must pay for such services twice a week.

BSEA #5011 OCTOBER 13, 1981
ETHAN C.

PRELIMINARY STATEMENT - Ethan C. is a 6 year-old boy enrolled in a collaborative pre-academic program. Ethan experiences expressive language difficulties as well as social and emotional problems interacting with people. He has generally been described as developmentally delayed, avoiding eye contact and withdrawing from his environment. At one time he took retalin but this has since been stopped. According to testimony Ethan has had musical skills and interests since early childhood. It was recommended by a speech therapist that he be a candidate for music therapy in order to use it as a stepping stone for related developmental skills. A music therapy evaluation was performed and it was determined that Ethan could benefit from this therapy. The school has offered and the parent has accepted a plan which includes a self-contained class, 2 hours per week of speech and language therapy and an hour per week of adaptive physical education.

ISSUE - Should the school committee be required to pay for music therapy as part of the IEP?

FINDINGS - Since Ethan has progressed in his past plan without music therapy, and since he has never formally gone to music therapy, the hearing officer found that it was not a required part of the IEP.

BSEA #5066 OCTOBER 26, 1981
GREGORY B.

PRELIMINARY STATEMENT - Gregory is a five year old child who was born with spina bifida and hydrocephalus. He has very little sensation from the waist down and cannot walk independently without wearing leg braces and holding onto a walker. His fine motor skills and social/emotional development are below age expectation.

His family moved from one community to another. The new community could not find an analagous placement to his previous 502.8 pre-school program which included physical and occupational therapy. Since one could not be found, the Y.M.C.A. summer program was suggested and an agreement signed with parents. However, this never materialized because there was no more space in the program. A team meeting was held that fall and it was agreed that Greg was to now attend the Y.M.C.A. pre-school program. No provision was made for the following summer but the team would reconvene in May. At the reconvening it was determined that Greg would not be provided summer school because the school felt its requirements did not extend beyond physical and occupational therapy which it proposed to continue.

ISSUES - 1) Was the summer program consisting of occupational and physical therapy services proposed, the least restrictive adequate and appropriate educational program for Greg for the summer?

2) Did the town fulfill its responsibility to implement the Everett IEP which was in effect when the family moved?

FINDINGS - The occupational and physical therapy services provided to Greg during the summer constituted an adequate and appropriate summer program. According to the hearing officer the recommendations did not support a finding that Greg was likely to regress substantially in the absence of a classroom program.

The hearing officer further found that delay in implementation of the 1980 summer program was occasioned by neither bad faith nor neglect and does not warrant an award of compensation or services.

I.E.P.

In this section of the PEP, the reader will find some common questions and answers about the Individualized Education Plan (IEP) and information that explains the various parts of the IEP.

THE INDIVIDUALIZED EDUCATION PLAN (IEP)

Pursuant to federal statute, the individualized educational plan for each child must include: "(a) a statement of the child's present levels of performance; (b) a statement of annual goals, including short term instructional objectives; (c) a statement of the specific special educational and related services to be provided to the child, and the extent to which the child will be able to participate in regular educational programs; (d) the projected dates for initiation of services and the anticipated duration of the services; and (e) appropriate, objective criteria and evaluation procedures and schedules for determining, on at least an annual basis, whether the short term instructional objectives are being achieved." (121a.346 Federal Register, Vol. 42, No. [illegible], August 23, 1977.)

[illegible] completed IEP format must be used when a student has [illegible] an initial evaluation or a re-evaluation, or when review [illegible] in movement to a more restricted protype.

I.E.P.

SOME COMMON IEP QUESTIONS AND ANSWERS

Linda Brouillette and Patricia A. Shank

Q. Can I change my mind about my child's placement after I've already signed my acceptance of the IEP?

A. Yes. You have the right to change your mind about acceptance of the plan at any time regardless of whether the stated time of the plan (usually one year) has elapsed or not. If you should decide to do this, a new meeting will be scheduled for the team to reconvene.

Q. Can I come to the IEP meeting with suggestions for specific goals I feel should be included in my child's plan?

A. Yes, you are encouraged to do so. Each suggestion will be discussed at the IEP meeting and incorporated in the plan if [illegible] at that time.

Q. [illegible] refuse to give permission for an evaluation?

A. Yes. However, it would be better to meet with the team or its representative to present your point of view and work together toward a solution.

Q. Can I bring someone with me to the IEP meeting who knows special education [or who works with my child, etc.]?

A. Yes. You have the right to bring ANYONE to the meeting with you as a support, advocate, professional or friend.

Q. Will I be advised when my child has attained or failed to attain any of the goals as outlined on the IEP?

A. Yes. Semi-annual reports are required by law as is a yearly review of your child's progress. You may also request progress information at any time not just during scheduled meetings.

Q. I have received my child's IEP and disagree with one of the goals and it's related objectives. Can you change them?

A. Yes, but it would be advisable to reconvene the team so that the changes you have in mind can be discussed.

Q. [illegible] my child's suggested educational plan?

[illegible] The plan must be acceptable to you and be approved by you.

Q. After an evaluation or yearly review meeting has taken place, when can I expect to see a final written form of the Educational Plan for my child?

A. You can expect to receive the Plan within ten working days after the meeting.

Q. Do I have to sign the Plan immediately upon receiving it?

A. No. Take the time you need to study the plan and fully understand its contents. If it is presented to you at the school, feel free to take it home and study it. Keep in mind, however, that the school does need your signature within a reasonable period of time in order to keep your child in his/her special education placement.

Q. What happens to my child's Educational Plan if we move to another town or state?

A. The current Educational Plan should be sent to your child's new school. This school should propose a similar program that you agree to or the evaluation team should meet to discuss options.

Q. What do I do if my child's Educational Plan is not being carried [illegible] I feel it is not working for my child?

[illegible] can request that the evaluation team be reconvened so that you can discuss your concerns. If they are not resolved, speak to the local Superintendent and School Committee. If this does not expedite the matter, begin preparations for using the Appeals Process established by the law.

Q. **Who can help me if I must prepare to use the Appeals Process?**

A. If after talking to the person in charge of the special education program, you feel that the answers given to any of your questions are not satisfactory, you might want to contact:

o the Regional Office of Special Education

o the nearest Advocacy Center

o the state's Office for Children

I.E.P.

The INDIVIDUALIZED EDUCATIONAL PLAN (IEP) is a statement of the school's plan for the education of your child. It includes a statement of his/her present levels of educational performance, a listing of the special education classes and programs your child will participate in, and the goals, objectives, teaching techniques and evaluation methods that will be utilized in each. Interspersed within the Plan is other information relating to your child's education.

The following sections contain brief explanations of each part of the IEP. Each explanation corresponds to a numbered or lettered part of the sample IEP attached.

1. STUDENT IDENTIFYING INFORMATION - this section includes:
   a) Time period the IEP covers, usually one year.
   b) Type of meeting being held:
      Initial - First evaluation in a particular school
      Review - Mandatory yearly review of a plan that is in effect
      [illegible] - Mandatory three-year reassessment which includes testing.

2. [illegible] - Any person attending the meeting must sign in [illegible] and indicate his/her role. This is simply an attendance record and your signature here does not signify agreement or disagreement with the proposed plan.

3. STUDENT PROFILE - a narrative description of your child. It includes performance level, strengths, weaknesses, learning style, and

any physical restrictions to his/her learning.

4. SPECIAL EDUCATION SERVICE DELIVERY - a listing of special education services and programs to be provided including:
   a) Type of service, e.g., speech therapy, leisure education, therapeutic recreation, language training, an academic class, adjustment counseling, etc.
   b) Focus for goal numbers - goal numbers of objectives appearing later in the plan that correspond to the service listed.
   c) Type of setting - the setting in which the listed service will be provided.
   d) Location - where the service will be provided.
   e) Personnel - who will perform the service to be provided.
   f) Projected date the service begins - when the service will begin.
   g) Frequency and duration - amount of time per day and week the service will be provided.
   h) Total hours per week - total time per week the service will be provided.

5. [illegible] [illegible] - what criteria will be used to decide when [illegible] spend a greater portion of time in a setting closer [illegible], i.e., a "regular classroom" in which students of the [illegible] receive educational services.

6. ANNUAL/DAILY LENGTH OF PROGRAM and TRANSPORTATION PLAN - here the total number of hours per day and days per year your child will receive services is indicated. Immediately following this, is the plan for transportation for your child.

7. ADDITIONAL INFORMATION - A variety of information related to the program which is prescribed to meet the individual needs of the student is entered on this section of the IEP, including but not limited to:

a) the classes or areas in which the student will be mainstreamed, including a description of the physical education program, and a description of the private to public school transitioning program, if applicable.

b) recommendations regarding state-mandated basic skills or curriculum testing for students at appropriate grade levels and in appropriate program prototypes. Some students are exempted from all or parts of the testing. Note separate PARENT NOTIFICATION/WAIVER FORM attached to IEP (page 7).

c) An indication of the need for continuing services to be provided by a human service agency (pursuant to Chapter 688) for students who are two years prior to graduation or age 22. (This is when Chapter 766 services end.) Students with severe disabilities who will not be able to work 20 hours per week would qualify for a transitional plan which is developed for the purpose of facilitating their transition from school to adult human services.

d) An indication of whether or not your child's disability might prevent him/her from following the regular disciplinary code of the school. If s/he cannot, an alternate plan for discipline will be described.

e) An expectation regarding graduation, the criteria for graduation, and the plan for meeting those criteria, for students fourteen years of age or older.

f) A justification if the daily or annual duration of the student's total educational program is different from that which is regularly provided.

g) A description of support services which will be provided to teachers.

8. STUDENT CENTERED GOALS - The general student centered goals correspond to your child's specific areas of need.

a) Priority Number - each goal is assigned a number indicating the order of priority.

b) Current Performance Level - a statement of your child's current performance level within the areas of need. Each performance level should represent the entry level skills for instruction by specifically stating what your child can do now.

c) General Student Centered Goals - are the skills and behaviors your child can be expected to achieve during the time of this plan.

d) Teaching Approach - On this section of the IEP, the teaching approach and methods suggested to help your child meet the stated goals are indicated. In addition, it includes the evaluation techniques which will be used to assess your child's progress toward achieving the goals.

9. SPECIFIC STUDENT CENTERED OBJECTIVES - are based upon the general goals. They indicate the behavior or action which will take place, the conditions under which the behavior will be performed, and the criteria which will be used to measure your child's success. Each objective is assigned a number indicating order of priority. For

each objective, the corresponding Goal Number from the preceding page is entered in the left column. The columns on the right are utilized to check and date the quarter(s) during which the objectives will be addressed.

10. RESPONSE TO EDUCATIONAL PLAN - The top section is reserved for your response to the plan that has been presented. If your child is 18 years of age or older, s/he signs it. Check the option of your choice, sign the form and date it. Return it to the school. At the bottom of the page, the special education administrator and the building administrator must sign the form stating that the goals included in the Plan are those of the evaluation team and the services listed will be provided.

INDIVIDUALIZED EDUCATIONAL PLAN

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PAGE 1 OF 6

SPECIAL EDUCATION DEPARTMENT
AYER PUBLIC SCHOOL SYSTEM
FORT DEVENS ELEMENTARY SCHOOL
FORT DEVENS, MASSACHUSETTS 01433

1

Ⓐ File Opened: [illegible] Date:______

Meeting Date: ______
Ⓑ Type of Meeting Held:
Initial Evaluation:
Review:
Re-Evaluation:

Date 3 Year Re-Evaluation Due:______

Identification No:______
School:______
Grade:______
Student's Dominant Language:______
Language of Home:______
Prototype:______
Liaison Name:______
Liaison Position:______

Student Name:______ Birthdate:______ Home Phone No:______

Parent(s) Name(s):______ Address:______ Work Phone No:______

TEAM PARTICIPANTS

2 Signature, if in attendance	Name	Role/Assessment Responsibility
		Chairperson/

STUDENT PROFILE, including but not limited to the
performance, [illegible] style:

3

[illegible]

4

Type of Service	[illegible]	[illegible] of Setting				
	[illegible] Co-[illegible] Services	[illegible]	[illegible]	[illegible]	[illegible]	
Ⓐ	Ⓑ					
				Ⓒ		

[illegible]

5 [illegible]

6 ANNUAL/DAILY DURATION OF PROGRAM: ___Days per

TRANSPORTATION PLAN: (Check One)

___Regular
___Parent-
___Special
______

limited to the child's performance level, measurable physical constraints on such

[illegible] of Setting				Location	Personnel	Projected Date Service Begins	Frequency and Duration of Service per Day/Week	Total Hours per Week
[illegible]	[illegible]	[illegible]	[illegible]					
				Ⓓ	Ⓔ	Ⓕ	Ⓖ	Ⓗ
	Ⓒ							
[illegible] Hours of Special Education Service Delivery Per Week:								

[illegible] including entry skills to be met by the student and accommoda-
[illegible]

___Days per Year, ___ Hours per Day

___Regular Transportation
___Parent-Provided Transportation with Reimbursement
___Special Transportation as follows:____
____

7 ADDITIONAL [illegible] a description of the child's participation in regular education and physical education, [illegible] modified testing programs, a description of the program for transitioning from [illegible] information:

Ⓐ

Ⓑ

Ⓒ

Need for Continuing Services: For students two years prior to graduation or age 22, the TEAM has determined that there ____IS, ____IS NOT a need for continuing services to be provided by a human service agency.

Ⓓ

Discipline: The student's handicapping condition requires a modification of the rules and regulations outlined in the student handbook. ___No ___Yes If YES, describe modifications below.

Ⓔ

Graduation/Diploma: For students fourteen years or older, the TEAM has determined that the student
Ⓕ ___IS expected to graduate in ____________________, ___IS NOT expected to graduate.
(Month/Year)
If the student is expected to graduate, the criteria for graduation and the plan for meeting those criteria are noted below:

8

PRIORITY NUMBER	CU[illegible]CE LEVEL	GENERAL STUDENT CENTERED GOALS	TEACHING APPROACH AND METHODOLOGY MONITORING AND EVALUATION TECHNIQUES SPECIALIZED EQUIPMENT AND MATERIALS
Ⓐ		Ⓒ	Ⓓ

9

PLAN COVERS THE PERIOD FROM :________ TO:________

SPED 766-5
PAGE 5 OF 6

Goal Number	Objective Number	SPECIFIC STUDENT CENTERED OBJECTIVES	QUARTERS DURING WHICH OBJECTIVES WILL BE ADDRESSED			
			1	2	3	4
			From:___ To:_____	From:___ To:_____	From:___ To:_____	From:___ To:_____

10 **RESPONSE TO [illegible]** Parent(s)/Guardian/Surrogate Parent/Student over age 18.

In the space [illegible] option(s) of your choice, sign and date this form, and make any comments you wish. You may [illegible] evaluation under the following circumstances: If you postpone a decision, if you reject the plan in [illegible] the finding of no special needs, if you reject the plan in part.

[illegible]

___ I [illegible] in full.

_✓_ I [illegible] special needs.

___ I postpone a [illegible] the completion of an independent [illegible].

___ I request an independent evaluation.

___ I reject the educational plan in full.

___ I reject the finding of no special needs.

___ I reject the following portions of the educational plan with the understanding that the portions which I accept will be implemented immediately.

Signature: ______________________ Date: ______________
(Parent/Guardian/Surrogate Parent/Student Over Age 18)

Comments: ______________________

I certify that the goals in this plan are those recommended by the TEAM and the indicated services will be provided.

Principal: ______________________ Special Education Administrator: ______________________
(Signature/Date) (Signature/Date)

If placement outside the local education agency is recommended, I certify that ______________________ (Facility Name/Address) is able to provide the services stated in this plan.

Director of Accepting Facility: ______________________
(Signature/Date)

REV. 9/86

STATE MANDATED TESTING PROGRAMS

Student: ______________________ Grade: ________ School: ______________________

State mandated ______________________ will be given to all students in grade _____
(Basic Skills/Curriculum Assessment)

in ______________. [illegible] ______________________, is eligible to participate in the testing
(Month/Year)

program which consists of [illegible] the following areas: ______________________

____

You should know that although testing will be appropriate for most special needs students, modifications to the testing procedures may be made when necessary. These modifications would be similar to those which are usually made in the child's instructional program.

Under Massachusetts law, parents may excuse their child from taking all or part of the test. If you do not want your child to participate, please check the appropriate space(s), sign and date this form, and return it to ______________________ by: ______________________
(Name) (Date)

[illegible] If you do not respond in writing on this form, testing will be administered on the scheduled date.

__ I do not want my child to participate in the state testing program described above.

__ I do not want my child to participate in the following areas of the state testing program described above:

____

____

____
(Parent Signature)

______________________ ______________
(Date)

NEW 9/86

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Identification No.:__________
School:__________
Grade:__________
Prototype:__________
Review Date:__________
Plan covers [illegible]
____

AMENDMENT
to be attached to
INDIVIDUALIZED EDUCATIONAL PLAN
dated__________ to__________

TEAM PARTICIPANTS:
____
____
____
____
Liaison:__________

Student Name:__________ Address:__________

[illegible]

SPECIAL EDUCATION SERVICE DELIVERY CHANGES ONLY: Type of Service	Focus on Objective Numbers	Type of Setting					Location	Personnel	Projected Date Service Begins	Frequency and Duration of Service per Day/Week	Total Hours per Week
		Class	Small Group	Individual	Regular	Special					
							Total hours of special education service delivery per week				

I certify that the goals stated in this plan are those recommended by the TEAM and that the indicated services will be provided.

Principal:__________ (Signature/Date)

Special Education Administrator:__________ (Signature/Date)

Director of Accepting Facility:__________ (Signature/Date)

RESPONSE - Circle one: Parent(s)/Guardian/Surrogate parent/ or Student over age 18, sign next to your choice.

I accept the educational plan as amended.__________ (Signature/Date)

I do not accept the educational plan as amended.__________ (Signature/Date)

I postpone a decision until a re-evaluation is completed.__________ (Signature/Date)

Goal Number	Objective Number	MODIFICATIONS TO SPECIFIC OBJECTIVES	Quarters during which objectives will be addressed			
			1	2	3	4

SPED 7[illegible]-4
PAGE 1 OF 3

COMMONWEALTH OF MASSACHUSETTS

DEPARTMENT OF EDUCATION - DIVISION OF SPECIAL EDUCATION

DIAGNOSTIC PLACEMENT PLAN

Prototype: 502.9

Diagnostic Placement Covers the Period
From: ______________ **to:** ________________

Date of this Meeting: ________________

Progress Meeting Dates:(1) ________________
(2) ________________

Date TEAM Must Convene: ________________

Identification #: ____________________

School: ____________________

Grade: ____________________

Student Name: ______________________ **Birthdate:** ______________ **Home Phone #:** ______________

Parent(s) Name(s): ______________________ **Address:** ______________ **Work Phone #:** ______________

TEAM PARTICIPANTS

Signature, If in Attendance	Name	Role/Assessment Responsibility

[illegible]	DIAGNOSTIC PROCEDURES TO BE EMPLOYED	RESULTS
1.	1.	1.
2.	2.	2.
3.	3.	3.
4.	4.	4.
5.	5.	5.

PROGRAM DESCRIPTION (Total Program)

A. Daily Duration of Total Program: ____________ hours per day

B. Service Delivery:

[illegible]	[illegible]	Facility	Personnel

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PAGE 3 OF 3

[illegible] Parent(s)/Guardian/Surrogate Parent/Student Over Age 18

[illegible] of your choice, sign and date this form, and make any comments you wish. [illegible] under the following circumstances: If you postpone a decision, if you reject [illegible] the plan in part.

[illegible]

___ I accept the plan for diagnostic placement.

___ I reject the plan for diagnostic placement.

___ I postpone a decision until the completion of an independent evaluation.

___ I request an independent evaluation.

___ I reject the following portions of the plan with the understanding that the portions which I accept will be implemented immediately.

Signature: ______________________________ Date: ______________
(Parent/Guardian/Surrogate Parent, Student Over Age 18)

Comments: ______________________________

Special Education Administrator: ______________________________ Date: ______________
(Signature)

Director of Accepting Facility: ______________________________ Date: ______________
(Signature)

Regional Branch Office Action (If Applicable): ___ Approved ___ Not Approved

______________________________ Date: ______________
(Signature)

NEW 9/86

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COMMONWEALTH OF MASSACHUSETTS

DEPARTMENT OF EDUCATION - DIVISION OF SPECIAL EDUCATION

ADMINISTRATIVE EDUCATIONAL STATUS ASSESSMENT

TO: Local School District Administrator

FROM: Team Evaluation Chairperson

G.L. 71B, Chapter 766, Paragraph 319.1

Student's Name__________________________ School____________________

Address_______________________________ Grade Level_________________

Assessment Prepared by____

Title___________________________________ Date____________________

I. **EDUCATIONAL HISTORY** (In the column marked notes, please include references to any special programming, promotions, retentions, etc. If school attended is not located in Massachusetts, please indicate state as well as city.

School Year	Grade	School Attended (Location)	Notes/Comments

II. **Narrative Statement of Student's Current Standing:**

III. **Overview of Student's School Progress:** (This statement should include standardized achievement test scores, unusual attendance patterns, any unusual program interruptions and behaviors. Attach additional pages, if necessary.

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Telecommunications

The next section of PEP describes telecommunications or the use of computers for networking and retrieving information. Schole is the telecommunications network developed at Boston University as part of the project entitled, "Advancing Educational Techniques through a Statewide Recreation Network." Basic information about this system has been included here.

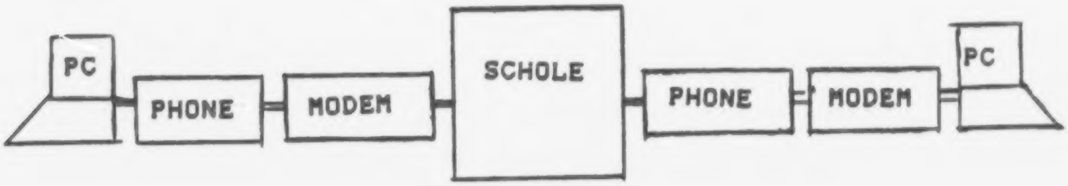
ELECTRONIC NETWORKING WITH COMPUTERS

by Victoria DeSalvatore

Since the beginning of time, people have devised ways to communicate with one another. Spoken language and written communication have been the most traditional ways. We are in a unique position in history to combine these two modes with the aid of computer technology. Computer advances have served to enhance communication in specialized ways. Telecommunications or networking using computers has combined the immediacy of the telephone with the availability of information. By using these technologies people can be linked to other people and share information and resources in new ways.

WHAT IS TELECOMMUNICATIONS?

Telecommunications is people talking to people through computers. The computers "talk" to each other over ordinary telephone lines. The computers are connected to the telephone lines through a device called a modem.



HOW DOES IT WORK?

Any home or personal computer can be connected to a modem. The modem connects to the telephone using the direct telephone line in your home or office. The computer dials a special telephone number to a larger computer. When the larger computer "answers" and a connection is made (you would hear a high pitched squeal) you are connected to the network.

HOW MIGHT PARENTS/CONSUMERS BENEFIT FROM A NETWORK?

o Networking enhances communication. Communicating with other people with similar interests or concerns can be an ongoing process, not limited to monthly meetings or yearly conferences. The network participants are the most information-rich component and the "experts" with whom you can communicate.

o Information can be shared regularly so that current newsletters or bulletins are always available.

- Gathering information through bulletin boards and databases is an easy, desktop function rather than a trip to the local library or organization office.

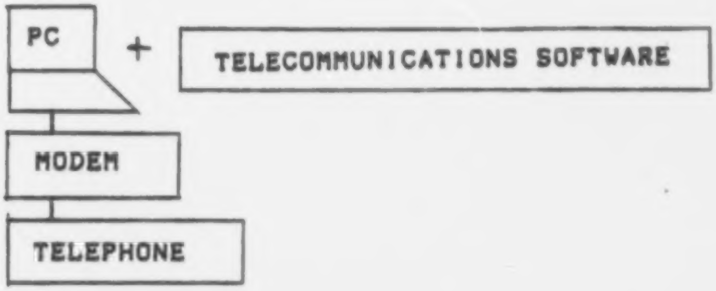
WHAT KINDS OF INFORMATION ARE AVAILABLE IN NETWORKS?

Networks can be broken down into two basic categories that describe their features. Not all networks contain both categories.

1. Interactive - Users can add or request information through the exchange of letters, bulletin boards, or forums.
2. Databases - Large files of data available for reference. The user reads the resource information but does not interact with the provider.

WHAT EQUIPMENT IS NEEDED?

To use any telecommunications network from a home computer you need:



WHAT IS SCHOLE?

Schole is a telecommunications network. It has communications features to link people through mail messages, bulletin boards, forums and live conferencing. The databases contain information resources in many areas of interest. This combination allows users to contribute their expertise as well as take advantage of information stored online. Through this sharing of information and communication, a network has evolved.

HOW DID SCHOLE START?

Schole became operational in March 1985. Prior to that, the need for efficient communication and information sharing was realized through the Statewide Recreation Network. A way to share large amounts of timely information with many people was needed. A computerized network was more efficient than the traditional mail service or telephone calls. Delays in the delivery of information on paper pointed towards the instantaneous delivery that is possible through the electronic computer medium.

I HAVE NEVER USED A COMPUTER, CAN I USE SCHOLE?

Yes! In order to use Schole you must be able to read and type short English words. No specialized computer training is needed. Schole is "user friendly" which means help is always available by typing a "?" The choice of words you have is on the screen at any time. You are prompted to make a selection on the "menu". Within a short time most users become experts on the system.

HOW DO I JOIN THE SCHOLE NETWORK?

The Schole network is a membership network. A one-time membership fee of $20.00 is the starting cost. To connect to the network the fees are:

$.16/per min.	from 6 p.m. - 7 a.m.
$.33/per min.	from 7 a.m. - 6 p.m.

HOW DO I PAY?

The $20 membership fee is payable by cash, check or money order when you complete your application. The connect time can be billed a credit card (MC, VISA, AMEX) or directly through the mail ($3.50 per month billing charge).

THIS IS A SAMPLE OF WHAT IS FOUND ON SCHOLE.

```
connect

Username:  DUCKY
Password:
```

your name

```
Hello DUCKY

Welcome to SCHOLE
Copyright 1985 by Trustees of Boston University
Hosted by General Videotex Corporation, Copyright 1986

Logon at    : 26-SEP-1986 09:52:52
Last Logon : 23-SEP-1986 13:30:45



Schole Main Menu:

About Schole           Mail
Bookstore              Professional Directories
Bulletin Boards        Recreation
Education              Research
Employment             Specialized Groups
Forum                  Teleconferencing
Grants and Funding     Travel
Hotlines--Support      HELP
Law                    EXIT
```

type something from the menu

```
MAIN>What do you want to do? about schole


About Schole Menu:
```

a second menu appears

```
Introduction
Guided Tour
Profiles
Settings for your computer
Usage History
EXIT

ABOUT SCHOLE>(Please Select an item) profile
```

Here users may add their profiles or read about other members of the network, change settings for computers and check online history. A brief introduction and guided tour are available for individuals wanting a refresher.

```
Schole Main Menu:

About Schole            Mail
Bookstore               Professional Directories
Bulletin Boards         Recreation
Education               Research
Employment              Specialized Groups
Forum                   Teleconferencing
Grants and Funding      Travel
Hotlines--Support       HELP
Law                     EXIT


MAIN>What do you want to do? law
```

↙ type an item from the menu

```
Law Menu:

Disability Advocates Bulletin
Recreation & Parks Law Reporter
EXIT


LAW> Disability Advocates Bulletin

Current Issue
Search Back Issues
```

The purpose of this Bulletin is to provide legal, administrative, and resource information to individuals with disabilities and their advocates. If you know of specific items which should be included, please notify Harry Beyer, Pike Institute, Boston University School of Law, 765 Commonwealth Ave., Boston, MA 02215 (617) 353-2904.

```
MAIN>What do you want to do? recreation

Recreation Menu:

Resources
Professional Preparation
EXIT

RECREATION>(Resources, Professional): Resources

Search on what criteria?
     CITY
     STATE
     KEYWORD


The Recreation resources listed here have been compiled from
contributions from the Statewide Recreation Network.  If you
know of a program or facility which is not included, send
mail to SCHOLE with your contribution.  You may search for a
program in a certain town, state or by a keyword.



MAIN>What do you want to do? travel

TRAVEL & LEISURE Menu:

City Profiles                      Reservations and Information
Country Profiles                   Services for Travelers
Group and Meeting Planner          Tips and Guides
News and Bulletins                 Exit
Official Airline Guide (OAG)

TRAVEL> Which service? city

Which CITY? boston

BOSTON, MASSACHUSETTS

Additional topics available:

AIRPORT INFORMATION               ARTS CALENDAR
CAPE COD                          CATERING
COLLEGE SPORTS                    DINING
GENERAL INFORMATION               GEOGRAPHY
HISTORIC SITES                    LOCAL HOLIDAYS-CELEBRATIONS
LODGING                           MAP
MARTHAS VINEYARD & NANTUCKET      MUSEUMS
NORTH SHORE                       PATRIOTS HOME GAMES
RED SOX 1986 SEASON INFO          SHOPPING
SIGHTSEEING SERVICES              SOURCES OF INFO
SOUTH SHORE                       THEATER
```

SCHOLĒ

TM

Scholé (TM) (sko-LAY)* is a network linking people and information via computers. This research-and-service project of the School of Education at Boston University is fully operational and capable of serving individuals and professional groups that are national or international in scope. It is a membership network.

Personal computers expand your communications and information-gathering abilities by using a microcomputer, a modem (the device which connects your personal computer to a telephone), and an ordinary telephone. Your world of communicating expands to telecommunications! Sending and receiving messages becomes instantaneous; access to databases is immediate using Dialog services and an online encyclopedia, or Scholé data. You can conduct research online and host live conferencing with users in other parts of the world. Through Schole you are able to interact directly with other members by simply dialing a local phone number.

Scholé is a menu-driven program. Easy commands and immediate online help are part of what makes Scholé user-friendly. To be an active part of the network, you are identified online by a unique "username" that you choose. It is not necessary for the user to know computer languages.

The menus are diverse and meet a variety of needs. At the present time, the following Scholé features are fully operational.

ABOUT SCHOLÉ - Information about the Scholé system and settings for your computer.
BOOKSTORE - Catalog services for online shopping.
BULLETIN BOARD - Public message system, read and post messages.
EDUCATION - Up-to-date opportunities.
EMPLOYMENT - Career opportunities.
FORUM - A comprehensive messaging system for ongoing discussions.
GRANTS AND FUNDING - What is currently available.
HOTLINES AND SUPPORT - Referral information.
LAW - Current legislation that my affect you.
MAIL - Private message system to send and receive mail.
PROFESSIONAL DIRECTORIES - Who's Who in related fields.
RECREATION - Resources and opportunities for professional preparation.
RESEARCH - Opportunities for information gathering.
SPECIALIZED GROUPS - Specific organizations online.
TELECONFERENCING - Live conferencing with one person or group.
TRAVEL - Information for your travel plans.
HELP - Explanation of Main Menu commands and other Scholé features.
EXIT - Sign off the Scholé system.

The word Scholé is taken from the Greek. It is the root word for our contemporary school.

HOW TO GET STARTED:

First, think of a Scholé username. Your username identifies you to others for electronic mail and conferencing, and serves as your account number for customer service and billing. It can be your initials, a nickname, or anything you would like. You may use up to eight letters and numbers, with no spaces or punctuation.

Second, complete, tear off, and return the Scholé Research Associate Application form. You will be called by a Scholé staff person to confirm your username and assign a password.

Third, dial up and sign on. You may dial directly, or place a local call via Tymnet, Uninet, or Datapac (Canada).

(a) Sign onto SCHOLÉ directly

1. Dial 617/576-0862.
2. When you have carrier, enter two carriage returns <CR>.
3. At "USERNAME" enter your SCHOLÉ name and <CR>.
4. At "PASSWORD" enter your password and <CR>.

(b) How to Sign on Using Tymnet

1. Dial your local Tymnet number.
2. When "PLEASE TYPE YOUR TERMINAL IDENTIFIER" appears, type "A" and <CR>.
3. When "PLEASE LOG IN" appears, type "GVC" and <CR>.
4. At "USERNAME" and "PASSWORD" enter as outlined above.

(c) How to Sign on Using Uninet

1. Dial your local Uninet number.
2. At "|x|" enter <CR><CR>.
3. At "SERVICE" type "GVC" and <CR>.
4. At "USERNAME" and "PASSWORD" enter as outlined above.

(d) How to Sign on Using Datapac (Canada)

1. Dial your local Datapac number.
2. Enter "." for 300 baud or ".." for 1200 baud.
3. Enter "Set 2:1,3:126" for full duplex allowing deletes.
4. Enter "p 1 3106,GVC:" <CR> (Tymnet).
5. At "USERNAME" and "PASSWORD" enter as outlined above.

To obtain your local numbers call:
Tymnet 1-800-336-0149
Uninet 1-800-821-5340 (In Missouri, 1-800-892-5915)

RESEARCH ASSOCIATE APPLICATION
BOSTON UNIVERSITY
LEISURE STUDIES PROGRAM
617/353-4478, 353-3295

SCHOLÉ PROJECT
SCHOOL OF EDUCATION
605 COMMONWEALTH AVENUE
BOSTON, MASSACHUSETTS 02215

Please accept my application for Research Associate of the SCHOLÉ PROJECT. I understand that SCHOLÉ is an information utility created in a research project of the Leisure Studies Program at Boston University and, as such, is presently in the development stage.

As a Research Associate, I agree to meet the following terms:

1] Pay a one-time membership fee.
2] Contribute to the development of SCHOLÉ, by providing the staff with feedback on menu items, user friendliness, keyword selection, etc.
3] Pay when due all online and storage charges incurred by me under the terms of this agreement.
4] Comply with the terms of the Scholé Association Agreement attached hereto and incorporated herein by reference.

NAME: ______________________________
AFFILIATION: ________________________
ADDRESS: ____
CITY: ____________________________ STATE: _____________
ZIP: __________ PHONE: [ ] ______________________

PERMANENT ADDRESS IF
DIFFERENT: ____
____

MEMBERSHIP FEE: Check or money order enclosed with this application.
BILLING FOR CONNECT TIME:
( ) MASTERCARD #____________________
Interbank #__________ Exp.Date________
( ) VISA #__________________________ Exp.Date________
( ) AMEX #__________________________ Exp.Date________
( ) Direct Billing @ $3.50 per month surcharge

Please select two usernames (NOT a password!) so others can mail to you or find you online (the second is in case your first choice is taken). Some samples: KELLS, MARYMAX, TOLKEN, etc.

1) _/_/_/_/_/_/_/_/ or 2) _/_/_/_/_/_/_/_/

Signature: ______________________
I have read and agree to the terms on the reverse side.

Please also include a word you will NOT forget (other than your password), like your mother's maiden name . . . because, if you forget your password, we will not tell you what it is unless you give us that word for security. ________________.

Boston University's policies provide for equal opportunity and affirmative action in employment and admission to all programs of the University.

TERMS OF THE SCHOLÉ ASSOCIATION AGREEMENT

1. SCHOLÉ consists of information in databases, software, and computing services which are made available by an appropriate information utility. These terms, together with operating instructions in print or online, constitute the entire agreement for use of the SCHOLÉ system and supersede all other communications and documents.

2. Upon notice published online or otherwise communicated to Research Associate, Scholé may modify these terms.

3. The SCHOLÉ system is provided on an "as is, as available" basis. No warranties express or implied, including, without limitation, those of merchantability and fitness for a particular purpose, are made with respect to SCHOLÉ.

4. The software in SCHOLÉ and in related databases is protected by copyright law. Research Associate may not reproduce, sell, publish, or in any manner commercially exploit any software obtained through the service nor may a Research Associate permit others to do so.

5. A Research Associate's use of the system will be subject to any credit limits and terms established for the use of Research Associate's credit card, or if direct billing is established, any credit limits and periodic minimum amounts established by Scholé or the billing agent designated by Scholé. Rates are subject to change upon thirty (30) days' notice. Direct-billed accounts are payable upon receipt.

6. This agreement will be performed in, and governed by, the laws of the Commonwealth of Massachusetts.

7. Research Associate is solely responsible for the confidentiality of his/her password. Research Associate must change his/her password whenever such confidentiality may have been jeopardized. SCHOLÉ shall not be responsible for any costs or damages resulting from the unauthorized use of any password.

MEMBERSHIP FEE
Until April 30, the SCHOLE one-time membership fee is $20.00.

Effective May 1, 1987, one-time membership fees are as follows:

- Individual membership $35.00.
  This fee includes a user handbook and one-half hour free connect time (daytime rates).
- Institution membership $100.00.
  This fee includes up to five usernames billed to one account, one user handbook and one-half hour free connect time (daytime rates) per username.

Payment is due with the membership application. Checks may be made payable to Boston University, Schole Project.

USAGE CHARGES
Basic "Connect Time" covers the use of standard Schole services. All time is billed in one-minute increments. When accessing via Tymnet, Uninet or Datapac, a two-minute session minimum applies. These rates are effective for access at 300, 1200, or 2400 baud access.

Home Time (6 p.m. to 7 a.m. weekdays plus weekends and holidays)
* $10.00 per hour

Office Time (7 a.m. to 6 p.m. weekdays)
* $20.00 per hour

BILLING
Your online time can be billed to your Visa, American Express, or Mastercard credit card. Each month you will see your SCHOLE charges billed by General Videotex Corporation on your statement. There is no additional service charge for this billing option. Members who choose to be billed for their usage and pay by check are subject to a $3.50/month surcharge.

STORAGE CHARGES
You will be charged for information stored in files under your control. The first 25,000 characters (daily average for the month) are free; thereafter, the charges are $.16/month for each additional 1000 characters.

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* All fees are subject to change.

Organizations and Agencies

This section of the PEP provides the reader with the names and addresses of a variety of organizations and agencies. They have been arranged in the following order:

- **Advocacy** organizations (National and Massachusetts-based)
- **Disability-Specific** organizations
- **Employment** (organizations concerned with vocational rehabilitation and equal employment opportunities for people with disabilities
- **Professional** organizations (discipline-specific and general)
- **Recreation** agencies in Massachusetts providing services for people with disabilities
- **Special Recreation** organizations dedicated to promoting sports opportunities for all
- **Travel** organizations (dedicated to accessible travel)

DISABILITY-SPECIFIC NATIONAL ORGANIZATIONS

The list of organizations found on the following pages is arranged alphabetically and includes most major organizations. We encourage you to read through all the lists that follow since there might be more than one organization that can provide you with the information you are looking for.

In several cases, the name of an organization has been listed more than once. It may be found under DISABILITY-SPECIFIC ORGANIZATIONS and under PROFESSIONAL ORGANIZATIONS AND ASSOCIATIONS. If what you are looking for is not listed in this section, check the PEP section on RESOURCES FOR SIBLINGS.

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- **Recreation** agencies in Massachusetts providing services for people with disabilities
- **Special Recreation** organizations dedicated to promoting sports opportunities for all
- Travel organizations (dedicated to accessible travel)

ADVOCACY ORGANIZATIONS AND AGENCIES

An advocate is one who pleads in a court of law or one who defends, and supports the cause of another before the public.

There are a number of advocacy organizations in Massachusetts and throughout the nation that are dedicated to helping people help themseleves.

On the following pages, we have listed several of these. They are there to help!

ADVOCACY: MASSACHUSETTS

Boston Center for Independent Living
50 New Edgerly Road
Boston, MA 02115
617-536-2187
Provides advocacy, information and referral services; support and independent living for individuals aged 16+ who have mobility impairments.

Boston Self Help Center
18 Williston Road
Brookline, MA 02146
617-277-0080
Provides counseling services, advocacy, and peer support groups for people who have physical disabilities and chronic illnesses; the average age of consumers is 35.

Ecumenical Social Action Committee, Inc
Maggie Goodwin, Paula Najarian
P.O. Box 4
62 Atherton Street
Jamaica Plain, MA 02130
617-522-2555
Provides counseling/advocacy for vocational and educational needs; social services and pre-vocational programs for teens ages 10-21 with family problems.

Federation for Children with Special Needs
312 Stuart Street
Boston, MA 02116
617-482-2915
Provides advocacy, information and referral services.

Haverhill-Newburyport Council for Children
69 Summer Street
Haverhill, MA 01830
617-372-0161
Provides advocacy, information and referrals.

Human Rights Commission
City Hall, Room 309
455 Main Street
Worcester, MA 01608
617-798-8151
The Commission receives and investigates complaints of discrimination in the areas of education, employment, the administration of justice,

recreation, public accommodations, and housing; offers technical assistance in the area of affirmative action. (Serves Worcester area.)

Massachusetts Coalition of Citizens with Disabilities
18 Williston Road
Brookline, MA 02146
617-277-0080
Advocacy groups are organized regionally and work with disability issues pertaining to any age.

Massachusetts Commission Against Discrimination
1 Ashburton Place, Room 601
Boston, MA 02108
617-727-3990
Concerned with employment discrimination; receives and investigates complaints, holds hearings and orders remedial actions.

Massachusetts Commission for the Blind
110 Tremont Street
Boston, MA 02108
617-727-5526, 1-800-392-6450
Provides information, referral, advocacy for all ages; also has Fall River, Springfield and Worcester area offices.

Mayor's Commission on the Handicapped
P.O. Box 501
New City Hall Plaza - Room 622
Boston, MA 02134
617-725-3696
Provides information, referral, advocacy on all issues affecting persons with disabilities.

Office for Children
10 Amesbury Street
Lawrence, MA 01840
617-685-0262
Provides information, referrals and advocacy for families and children with disabilities.

Taunton Human Relations Commission
1 Leonard Court
Taunton, MA 02780
617-823-6546
The Commission receives and refers complaints of discrimination in the areas of education, employment, the administration of justice, voting rights, public accommodations, credit, and housing. It is concerned with discrimination based on race, color, religion, sex, national origin, age, and handicap. (Serves Taunton area.)

NATIONAL ADVOCACY

Advocates for the Handicapped
2200 Merchandise Mart
Chicago, IL 60654
312-822-0435
Legal advocates for civil rights, employment, housing, etc. Provides publications such as ADVOCATOR newsletter.

AFL-CIO Department of Community Services
815 16th St, N.W.
Washington, D.C. 20006
202-637-5189
Information on rehabilitation, mental health, substance abuse, fund raising, consumer counseling. Dedicated to developing working relationships with community social agencies.

American Coalition of Citizens with Disabilities (ACCD)
1200 15th Street NW, #201
Washington, DC 20005
Provides information, support and referral pertaining to issues affecting individuals with disabilities.

The Association of Junior Leagues, Inc.
825 Third Avenue
New York, NY 10022
212-355-4380
Facilitates and supports community projects for child advocacy, health, and disabilities and provides volunteer training publications, and an advisory organization for Junior Leagues.

Center on Human Policy
Syracuse University
216 Ostrom Avenue
Syracuse, NY 13210
315-423-3851
Provides information and written materials pertaining to the rights of individuals with disabilities. A major focus of the organization is on community organizing that will help consumers act on their own behalf to obtain their rights. The Center engages in legal advocacy, conducts sociological research and disseminates a wide variety of written materials.

Closer Look Information Center
1201 16th Street, NW
Washington, DC 20036
202-833-4163
The organization places special emphasis on the rights of individuals with disabilities. It encourages parents to press for the rights of their disabled children to an education equal in quality to that of their non-disabled peers, and for the rights of adults with disabilities to live a normal and productive life. Instructs parents on how to organize parent groups, gives technical assistance to coalitions working with individuals with disabilities, and supplies information packets on a number of issues pertaining to disabilities.

Disability Rights Center
1346 Connecticut Avenue NW
Washington, DC 20036
202-223-3304
Provides advocacy information and resources that pertain to legislation affecting the lives of individuals with disabilities.

Human Resources Center
I. V. Willets Road
Albertson, NY 11507
516-747-5400
A nonprofit organization for the education, training and placement of individuals who are disabled, mentally retarded and aged. Publishes reports and monographs.

Mainstream, Inc.
1200 15th Street, NW
Washington, DC 20005
202-833-1136
1-800-424-8089 (free hotline)
A nonprofit organization established to encourage the mainstreaming of people with disabilities in education and employment. Serves as a link between consumers, the business center and the Federal Government. Operates a hotline to answer queestions on compliance with the Rehabilitation Act of 1973.

Mental Health Law Project
1220 19th Street, NW
Washington, DC 20036
202-467-5730
An interdisciplinary public interest organization which attempts to define and protect the rights of persons who are mentally disabled and to stimulate improvements in public policies regarding their care, treatment, habilitation and community life. Publishes handbooks and newlstter.

U. S. Commission on Civil Rights
Washington, DC 20425
The Commission is an independent, bipartisan agency established by Congress in 1957 and directed to investigate complaints alleging that citizens are being deprived of their right to vote by reason of race, color, religion, sex, age, handicap, or national origin. Also, it studies and collects information pertaining to legal developments pertaining to above; serves as a national clearinghouse for information in respect to discrimination or denial of equal protection of the laws, and submits findings to the President and the Congress. Publishes a Civil Rights Directory which lists governmental and private agencies and organizations engaged in program activities pertaining to discrimination and equal protection.

U. S. Department of Education
Office for Civil Rights
400 Maryland Avenue, SW
Washington, DC 20202
202-245-7680
The Office is responsible for ensuring equality of educational opportunity and compliance with laws prohibiting discrimination in education based on race, color, national origin, age and disability. It conducts compliance reviews, receives and investigates complaints, seeks conciliation, conducts studies and surveys, publicizes findings, and provides training and technical assistance.

DISABILITY-SPECIFIC NATIONAL ORGANIZATIONS

The list of organizations found on the following pages is arranged alphabetically and includes most major organizations. We encourage you to read through all the lists that follow since there might be more than one organization that can provide you with the information you are looking for.

In several cases, the name of an organization has been listed more than once. It may be found under DISABILITY-SPECIFIC ORGANIZATIONS and under PROFESSIONAL ORGANIZATIONS AND ASSOCIATIONS. If what you are looking for is not listed in this section, check the PEP section on RESOURCES FOR SIBLINGS.

Alexander Graham Bell Association for the Deaf
Winifred H. Northcott, Ph.D.
3417 Volta Place, N.W.
Washington, DC 20007
202-337-5220
Provides information service for parents, libraries, health professions. Has a specialized library and publications about hearing impairments.

Allergy Foundation of America
118-35 Queens Boulevard
Forest Hills, NY 11375
718-261-3663
Provides information on a number of allergies including asthma.

American Brittle Bone Society
1256 Merrill Drive
West Chester, PA 19380
215-692-6248
Provides information pertaining to osteogenesis imperfecta.

American Cancer Society
777 Third Avenue
New York, NY 10017
212-371-2900
Provides general information and publications pertaining to cancer and its treatment.

American Diabetes Association
2 Park Avenue
New York, NY 10016
212-683-7444
Clearinghouse for information about diabetes.

American Foundation for the Blind, Inc.
Jasen Noyes, Jr.
15 West 16th Street
New York, NY 10011
212-620--2000
Clearinghouse for information; consultation to agencies; lending library; aids for people who are blind; publications available.

American Heart Association
7320 Greenville Avenue
Dallas, TX 75231
214-750-5300
Clearinghouse for information and publications pertaining to heart disorders.

The American Legion
Jack Carey
700 N. Pennsylvania Street
P.O. Box 1055
Indianapolis, IN 46204
317-635-8411
Provides rehabilitation, education, training and benefits for veterans who are disabled; publications available.

American Leprosy Missions, Inc.
The Rev. Roger K. Ackley
1262 Broad Street
Bloomfield, NJ 07003
201-338-9197
Provides medical, social rehabilitation, education, research; publications available.

American Liver Foundation
998 Pompton Avenue
Cedar Grove, NJ 07009
201-857-2626
Provides information pertaining to liver disorders.

American Lung Association
Ethelene J. Crockett, M.D.
1740 Broadway
New York, NY 10019
212-245-8000
Public and professional education and research; publications available.

American Mental Health Fund
P.O. Box 17389
Washington, DC 20041
703-790-8570
Provides information about and resources for mental health.

American Paralysis Association
4100 Spring Valley Road
#104, LB 3
Dallas, TX 75234
Provides information about spinal cord injury.

American Printing House for the Blind, Inc.
Watson B. Dabney
1839 Frankfort Ave.
Louisville, KY 40206
502-895-2405
Provides research, manufactures braille and talking books; provides large type catalogs, brochures.

The Arthritis Foundation
Clifford M. Clarke, CAE
1314 Spring Street NW
Atlanta, GA 30309
404-872-7100
Dedicated to research, community service, and informing doctors of developments in arthritis care; offers pamphlets, brochures, handbook for people with arthritis and their families.

Association for Brain Tumor Research
6232 North Pulaski Road, #200
Chicago, IL 60646
312-286-5571
Conducts research pertaining to brain disorders.

Association for the Care of Children's Health
3615 Wisconsin Avenue NW
Washington, DC 20016
202-244-1801
Dedicated to humanizing health care particularly as it pertains to children. Provides publications and periodicals.

Association for Children and Adults with Learning Disabilities
4156 Library Road
Pittsburg, PA 15234
Provides information and resources pertaining to the education of persons who have learning difficulties.

Association for Congenital Facial Paralysis, Inc.
928 Hanover Lane
Dyer, IN 46311
219-322-3389
Provides information about facial paralysis.

Association for Neurometabolic Disorders
5223 Brookfield Lane
Sylvania, OH 43506
419-885-1497
Provides information pertaining to neurometabolic disorders.

Association for Retarded Citizens of the United States
2501 Avenue J
Arlington, TX 76011
817-640-0204
Provides information and support for persons with mental retardation and/or delayed development and their families.

DISABILITY-SPECIFIC NATIONAL ORGANIZATIONS

The Association for the Severely Handicapped (TASH)
7010 Roosevelt Way NE
Seattle, WA 98103
206-523-8446
Provides information, support and resources pertaining to issues confronting persons with severe disabilities and their families.

Autism Services Center
101 Richmond Street
Huntington, WV 25702
304-523-8269
Provides information pertaining to autism and its treatment.

Blinded Veterans Association
Dr. George E. Stocking
1735 DeSales Street, N.W.
Washington, DC 20036
202-347-4010
Provides counseling, rehabilitation, educational training and publications (recorded and braille).

Cancer Information Clearinghouse
Office of Cancer Communications
National Cancer Institute
9000 Rockville Pike, Building 31, Room 10A21
Bethesda, MD 20205
800-4-CANCER
A clearinghouse of information and resources pertaining to cancer and its treatment.

Candlelighters Childhood Cancer Foundation
2025 Eye Street NW, #1011
Washington, DC 20006\202-659-5136
Provides information pertaining to childhood cancers and family support groups.

Center for Hyperactive Child Information, Inc.
P.O. Box 406
Murray Hill Station
New York, NY 10156
212-679-3959
Provides information, resources and support for families of children with behavioral disorders.

Council for Children with Behavioral Disorders
1920 Association Drive
Reston, VA 22091
703-368-3293
Provides information pertaining to a variety of behavioral disorders.

Council for Exceptional Children
1920 Association Drive
Reston, VA 22091
703-620-3660
Provides information and resources pertaining to the education of children with special learning needs.

Cri-du-Chat Society
Department of Human Genetics
Medical College of Virginia
Box 33, MCV Station
Richmond, VA 23298
804-786-9632
Provides information and support pertaining to Cri-du-Chat syndrome.

Cystic Fibrosis Foundation
6000 Executive Boulevard, #309
Rockville, MD 20852
301-881-9130
Provides information pertaining to cystic fibrosis.

Down Syndrome Congress
1640 West Roosevelt Road
Chicago, IL 60608
312-226-0416
Provides information, publications and support for families with a member who has Down syndrome.

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785
301-459-3700
Provides information, publications and support for individuals with epilepsy.

Families of Spinal Muscular Atrophy
P.O. Box 1465
Highland Park, IL 60035
312-432-5551
Provides information and support for families of individuals with spinal muscular atrophy.

Freidrich´s Ataxia Group in America
P.O. Box 11116
Oakland, CA 94611
Provides information for individuals and families affected by Freidrich´s Ataxia.

DISABILITY-SPECIFIC NATIONAL ORGANIZATIONS

Juvenile Diabetes Foundation
60 Madison Avenue
New York, NY 10010
Provides information and resources for the care and treatment of juvenile diabetes.

Lowe´s Syndrome Association
607 Robinson Street
West Lafayette, IN 47906
Provides information to families with a member who has Lowe´s syndrome.

Leukemia Society of America
800 Second Avenue
New York, NY 10017
Provides information about leukemia and present research efforts.

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
Provides a variety of information about birth defects; instrumental in fund raising efforts to support research.

Muscular Dystrophy Association
810 Seventh Avenue
New York NY 10019
Provides information to families and individuals who have MD.

National Association of the Deaf
814 Thayer Avenue
Silver Springs, MD 20910
Provides information about deafness and resources.

National Association for Down Syndrome
P.O. Box 63
Oak Park, IL 60303
Provides information about Down Syndrome and resources for families.

National Association of the Deaf-Blind
12573 S. E. 53rd Street
Bellevue, WA 98006
Provides information and resources to individuals who are deaf and blind and their families.

National Association for Sickle Cell Disease
3460 Wilshire Blvd., Suite 1012
Los Angeles, CA 90010
Provides information about and support for research concerning sickle cell disease.

National Federation of the Blind
1346 Connecticut Avenue, NW
Suite 212, Dupont Circle Building
Washington, DC 20036
Provides information about blindness and resources for living independently.

National Genetics Foundation
555 West 57th Street, Room 1240
New York, NY 10019
Provides information about and support research into genetic disorders.

National Multiple Sclerosis Society
205 East 42nd Street
New York, NY 10017
Provides information about the disease and resources for coping with it.

National Neurofibromatosis Foundation
70 West 40th Street, 4th Floor
New York, NY 10018
Provides information and support to families with a member who has neurofibromatosis.

National Organization for Rare Disorders
c/o National Huntington's Disease Association
1182 Broadway, Suite 402
New York, NY 10001
Provides information about rare disorders.

National Society for Autistic Children
1234 Massachusetts Avenue, NW
Suite 1017
Washington, DC 20005
Provides information about autism and the care and treatment of children affected.

Tourette Syndrome Association
41-02 Bell Blvd.
Bayside, NY 11361
Provides information and resources pertaining to children and adults with Tourette Syndrome.

United Cerebral Palsy Associations, Inc.
330 West 34th Street, 13th Floor
New York, NY 10001
Provides information about cerebral palsy and serves as a clearinghouse of information about local chapters of UCP.

GOVERNMENT AGENCIES

Administration on Developmental Disabilities
Office of Human Developmental Services
Department of Health and Human Services
330 Independence Avenue, SW
Room 3194
Washington, DC 20201

Architectural and Transportation Barriers Compliance Board
330 C Street, SW
Room 1010, Switzer Building
Washington, DC 20202

Division of Assistance to States Office of Special Education
400 Maryland Avenue, SW
Donohoe Building
Washington, DC 20202

National Information Center for Handicapped Children and Youth
P.O. Box 1492
Rosslyn, VA 22209

National Library Service for the Blind and Physically Handicapped
Library of Congress
1291 Taylor Street, NW
Washington, DC 20542

Office of Deafness and Communicative Disorders
Department of Education
Room 3416, Switzer Building
400 Maryland Avenue
Washington, DC 20202

Presidents Committee on Employment of the Handicapped
Department of Labor
1111 20th Street, NW, #600
Washington, DC 20036

EMPLOYMENT

NOTE: See also the next PEP section on PROFESSIONAL ORGANIZATIONS.

AMVETS (American Veterans of WW II, Korea and Vietnam)
Joseph R. Koralewski
1710 R.I. Avenue, N.W.
Washington, DC 20036
202-223-9550
Provides rehabilitation, employment services, counseling; publications available.

Council of State Administrators of Vocational Rehabilitation
1522 K Street, NW
Suite 610
Washington, DC 20005
A professional organization for delivery of services to people who are disabled. Publications available.

EPI-HAB, L.A., Inc.
5533 S. Western Avenue
Los Angeles, CA 90062
213-299-2305
Organization for re-integration of persons with epilepsy, work training, employment, socialization, counseling, sports, and recreation. Publications available.

Federation Employment and Guidance Service
114 5th Avenue
New York, NY 10011
212-242-9050
A job placement service offering educational and vocational guidance. Programs for persons who are developmentally disabled and mentally ill. Pamphlets and directories are available.

Goodwill Industries of America
9200 Wisconsin Avenue, NW
Washington, DC 20014
301-530-6500
Programs for vocational rehabilitation. Newsletter available.

President's Committee on Employment of the Handicapped
1111 20th Street, NW
Washington, DC 20036
202-653-5044
Involved in national education and information programs, training, rehabilitation and employment opportunities.

MEMBERS OF

THE PRESIDENT'S COMMITTEE ON EMPLOYMENT OF THE HANDICAPPED

Aerospace Industries Association of America, Inc.
Clayton Ruyle
1725 DeSales Street N.W.
Washington, DC 20036

Airline Pilots Association
John O'Donnell
1625 Massachusetts Avenue, N.W.
Washington, DC 20036

Alliance of American Insurers
1501 Woodfield Road
Suite 400 West
Schaumburg, IL 60195

Altrusa International
Verona Bordok
8 South Michigan Avenue
Chicago, IL 60603

Amalgamated Clothing and Textile Workers Union
Murray Finley
15 Union Square
New York, NY 10003

Amalgamated Transit Union
John Rowland
5025 Wisconson Avenue, N.W.
Washington, DC 20016

American Academy of Physical Medicine and Rehabilitation
Creston Herald
30 North Michigan Avenue
Chicago, IL 60602

American Airlines, Inc.
Robert Wick
P.O. Box 61616
DFW Airport, TX

PROFESSIONAL ORGANIZATIONS AND ASSOCIATIONS

The next section of organizations is divided into two parts: The first gives the names and addresses of the professional organizations to which many of the people who work with your child might belong. These organizations can provide you with additional information about a particular human service specialty.

The second section lists a number of organizations and associations that provide general information, publications and referrals.

In some cases, an organization has been listed in another section of PEP (see, for example DISABILITY-SPECIFIC ORGANIZATIONS and RESOURCES FOR SIBLINGS).

If there is a particular organization or association you were looking for that we have not included, we suggest you contact the National Information Center for Handicapped Children and Youth, P.O. Box 1492, Rosslyn, VA 22209.

SECTION ONE: ORGANIZATIONS AND ASSOCIATIONS FOR HUMAN SERVICE PROFESSIONALS

PROFESSIONAL ORGANIZATIONS AND ASSOCIATIONS

Academy of Dentistry for the Handicapped
Kurt King, DDS
1726 Champa St
Denver, CO 80202
303-573-0264
Dentistry, educational materials, referral system for dentists; publications available, professional organization.

American Alliance for Health, Physical Education, Recreation and Dance: Programs for the Handicapped
Dr. Julian U. Stein
1201 16th St N.W.
Washington, D.C. 20036
202-833-5547
Provides printed material for physical education, nature, aquatics and geriatrics. Operates the Information and Research Utilization Center (URIC); professional organization.

American Association on Mental Deficiency
Marjorie H. Kirkland
5101 Wisconsin AveNUE, N.W.
Washington, D.C. 20016
202-686-5400
Evaluates services and supports legislation concerning individuals with mental retardation and other developmental disabilities; publications available; professional organization.

American Association of Occupational Health Nurses, Inc.
Virginia L. Carlson, R.N.
575 Lexington AveNUE
New York, NY 10022
212-355-7733
A professional organization concerned with occupational nursing; Provides conferences, continuing education and publications.

American Association for Rehabilitation Therapy, Inc.
Errick Woosley, RRT, President
P.O. Box 93
North Little Rock, AR 72116
501-725-9100 x469
Has separate sections for adjunctive therapies; holds conferences; publications and information is available; professional organization.

American Association of Workers for the Blind, Inc.
Jerry Dunlap
1511 K. St., N.W.

Washington, D.C. 20005
202-347-1559
Dedicated to the promotion, development, and improvement of services to the blind; holds conferences; publications available; professional organization.

American Cancer Society, Inc.
Mrs. Albert D. Lasker
777 Third Avenue
New York, NY 10017
212-371-2900
Provides educational services and rehabilitation programs for mastectomees, laryngectomees, and ostomy patients; publications available.

American Coalition of Citizens with Disabilities, Inc.
Terrence J. O'Rourke
1200 15th Street, N.W., Suite 201
Washington, D.C. 20005
202-785-4265
Information collecting, advocate organization; provide workshops and publications. [See also, ADVOCACY]

American Congress of Rehabilitation Medicine
Thomas P. Anderson, M.D.
30 N. Michigan Avenue
Chicago, IL 60602
312-236-9512
Rehabilitation development; journals available, professional organization

American Dance Therapy Association
1000 Century Plaza
Suite 210
Columbia, MD 21044
301-997-2310

American Deafness and Rehabilitation Association, Inc.
Sue E. Ouelette
814 Thayer Avenue
Silver Spring, MD 20910
301-589-0880
Promote expansion of rehabilitation services to deaf adults; professional organization.

American Medical Association
Department of Environmental, Public, & Occupational Health
Theodore C. Doege, M.D.
535 North Dearborn Street

Chicago, IL 60610
312-751-6526
Advising and educating physicians; providing resources about handicapped persons relating to employment; publications available, professional organization.

American Red Cross
Jerome H. Holland
17 and D Streets, NW
Washington, DC 20006
202-737-8300
Provides aquatics, Special Olympics, rehabilitation for institutionalized persons; publications available.

American Occupational Therapy Association
Mae D. Hightower-Vandamm, OTR
6000 Executive Blvd.
Rockville, MD 20852
301-770-2200
Consultation, public information; professional certification; publications available, professional organization.

American Orthotic and Prosthetic Association
William Hamilton
1444 N. Street, NW
Washington, DC 20005
202-234-8400
Dedicated to communication between suppliers of products and services, legislation concerned with health care services; publications available, professional organization.

American Osteopathic Association
Edward P. Crowell
212 E. Ohio Street
Chicago, IL 60611
312-944-2713
Conducts research; promotes public health; provides educational materials; professional organization.

American Physical Therapy Association
Royce P. Noland
1156 15 Street, N.W.
Washington, DC 20005
202-466-2070
Provides education, research, publications; the national professional organization for Physical Therapists.

American Personnel and Guidance Association
Mary Maples
2 Skyline Place, Suite 400
5203 Leesburg Pike
Falls Church, VA 22041
703-820-4700

Provides guidance and counseling education, counselor development workshops; publications available, professional organization.

American Podiatry Association
Seward P. Nyman, D.P.M.
20 Chevy Chase Circle
Washington, DC 20015
202-537-4900
Clearinghouse; interest in podiatrists in serving people with disabilities; publications available, professional organization.

American Psychiatric Association
Melvine Sabshin, M.D.
1700 Eighteenth Street, N.W.
Washington, DC 20009
202-797-4950
Dedicated to making psychiatric knowledge available to other practitioners; publications available, professional organization.

American Speech, Language and Hearing Association
Margaret Byrne
10801 Rockville Pike
Rockville, MD 20852
301-897-5700
Encourages scientific study of communication disorders; provides professional certification; publications available, professional organization.

American Therapeutic Recreation Association
Melinda Conway Callahan, President, 1986-1987
3417A Sapula Road, Box 377
Sand Springs, Oklahoma 74063

A recently formed (1984) professional association for certified therapeutic recreation specialists and para-professionals. Provides information on therapeutic recreation practices particularly in clinical settings; active in supporting legislation affecting persons with disabilities; newsletter; professional organization.

The Association on Handicapped Student Service Programs in Post-Secondary Education
Ron Gibbens
Box 8256 University Station
Grand Forks, ND 58202
701-777-3425
Promotes equal rights and opportunities of students with disabilities in post-secondary education; provides a newsletter; professional organization.

National Coalition of Arts Therapy Associations
c/o Annmarie Pitman
655 15th Street, N.W.
Suite 300
Washington, D.C. 20005
202-639-4285

A Coalition of professionals representing the fields of Music, Dance, Art, and Drama Therapies and who work in a variety of clinical and educational settings.

National Recreation and Park Association
National Therapeutic Recreation Society
3101 Park Center Drive
Alexandria, VA 22302
703-820-4940
The National Therapeutic Recreation Society (NTRS) is one branch of the National Recreation and Park Association (NRPA) which represents professionals and para-professionals in therapeutic recreation; provides a newsletter; professional organization.

SECTION TWO: ORGANIZATIONS AND ASSOCIATIONS FOR INFORMATION AND REFERRALS

PROFESSIONAL ORGANIZATIONS AND ASSOCIATIONS

Bureau of Education for the Handicapped
US Office of Education
400 Maryland Ave., SW
Washington, DC 20202
202-245-9661
Coordination for training teachers, distribution of media and materials, and model programs.

CHAP (Children Have a Potential)
AF/SGPC-CHAP, Air Force Medical Service Center, Brooks Air Force Base
San Antonio, TX 78235
512-536-2031
Assists Air Force families with handicapped children. Provides counseling and parent groups. Air Force regulation available.

The Council for Exceptional Children
1920 Association Dr.
Reston, VA 22091
703-620-3660
A professional organization for the education of handicapped and gifted children and youth. Publications are available.

Council of State Administrators of Vocational Rehabilitation
1522 K Street, NW
Suite 610
Washington, DC 20005
202-638-4634
A professional organization for delivery of services to handicapped and deaf persons. Publications available

Damien Dutton Society for Leprosy Aid Inc.
616 Bedford Ave.
Bellmore L.I., NY 11710
516-221-5909
Society for research, rehabilitation services, and public education. Publications available.

Disabled American Veterans, National Service, Legislative Headquarters
807 Maine Ave, SW
Washington, DC 20024
202-554-3501
A national service program which supports legislation and scholarship Publications are available.

EPI-HAB, L.A., Inc.
5533 S. Western Ave.
Los Angeles, CA 90062
213-299-2305
Organization for re-integration of persons with epilepsy, work training, employment, socialization, counseling, sports, and recreation. Publications are available.

Epilepsy Foundation of America
Adolph L. Sahs, M.D.
1828 L. Street, NW
Washington, DC 20036
202-293-2930
National spokesman for people with epilepsy; advocacy; school education programs; Publications are available.

Federation Employment and Guidance Service
114 5th Avenue
New York, NY 10011
217-777-4900
A job placement service offering educational and vocational guidance. Programs for persons who are developmentally disabled and mentally ill. Pamphlets, and directories are available.

Federation of the Handicapped, Inc.
211 West 14th Street
New York, NY 10011
212-242-9050
Vocational rehabilitation, group work and recreation services.

The 52 Association, Inc.
147 East 50th Street
New York, NY 10022
212-752-1855
Organization for disabled armed service members. Services include driver training, rehabilitation, and recreation. Pamphlets are available.

Gallaudet College
7th and Florida Ave., NE
Washington, DC 20002
202-651-5005
A liberal arts college for persons who are deaf. Catalog available.

Girl Scouts of the USA Services for Girls with Special Needs
830 Third Ave.
New York, NY 10022
212-940-7500
Scouting organization for girls. Services include recreation, camping, sports, recreation, arts, service, skills. Catalog available.

Goodwill Industries of America
9200 Wisconsin Ave., NW
Washington, DC 20014
301-530-6500
Program for vocational rehabilitation. Newsletter available.

Helen Keller, International, Inc.
22 West 17th Street
New York, NY 10011
212-620-2100
Technical assistance to developing countries to help upgrade services for individuals who are blind, education, rehabilitation, and the prevention of blindness. Newsletter and brochures are available.

Human Resources Center
Willets Road
Albertson, NY 11507
516-747-5400
A resource center for education, training, placement, and research for individuals who are severely physically disabled, and/or retarded.

ICD Rehabilitation and Research Center
340 East 24th Street
New York, NY 10010
212-679-0100
A center for rehabilitation, treatment, training, research, professional development. A newsletter is available.

Industrial Home for the Blind
57 Willoughby Street
Brooklyn, NY 11201
212-522-2122
Rehabilitation training, library services in braille, large print books, talking books, and summer day camps for individuals who are blind and deaf-blind.

International Association of Laryngectomees
777 Third Avenue
New York, NY 10017
212-371-2900
An association for rehabilitation, information dissemination. Free speech lessons and publications are available.

International Handicapped Net
P.O. Box B
San Gabriel, CA 91778
213-282-0014
An organization for radio amateurs who are disabled. Publications are available.

The Joseph P. Kennedy, Jr. Foundation
Senator Edward M. Kennedy
1701 K. Street, NW, Suite 205
Washington, DC 20006
202-331-1731
A foundation for research and Special Olympics programs. A small scholarship program in physical education and recreation is available.

Junior National Association of the Deaf
Gallaudet College
Washington, DC 20002
An association to motivate young deaf people. Has an annual Youth Development Camp. Publications are available.

Library of Congress
National Library Service for the Blind and Physically Handicapped
Washington, DC 20542
202-882-5500
A free library service with recorded and braille books. Publications are available.

March of Dimes Birth Defects Foundation
1275 Mamaroneck Avenue
White Plains, NY 10605
914-428-7100
A foundation for research, public health education and fundraising. Publications are available.

PROFESSIONAL ORGANIZATIONS AND ASSOCIATIONS

The Menninger Foundation
P.O. Box 829
Topeka, KS 66601
913-234-9566
A foundation for research, education and preventive psychiatry. Publications include a scientific journal. This is a professional organization.

Muscular Dystrophy Association
810 Seventh Avenue
New York, NY 10019
212-586-0808
An association for research, grants, fellowships, diagnostic services, summer camping, transportation aid and fundraising. Publications are available.

National Association for Retarded Citizens
2709 Avenue East
P.O. Box 6109
Arlington, TX 76011
817-261-4961
An association for public education, family counseling, and advocacy. Functions as a clearinghouse with publications available. This is a membership organization.

National Association of the Deaf
814 Thayer Avenue
Silver Spring, MD 20910
301-587-1788
A clearinghouse for information relating to deafness and problems encountered by persons who are deaf. Publications are available.

National Association of the Physically Handicapped, Inc.
76 Elm Street
London, OH 43140
614-852-1664
This organization has committees for barrier free design, recreation, sports, a library, and transportation issues. A newsletter is published. This is a membership organization.

National Association of Private Psychiatric Hospitals
1701 K Street, NW
Suite 1205
Washington, DC 20006

202-223-6691
Association for sharing information for treatment planning, research, accreditation, education, and legislation. Publications are available from this professional organization.

National Association of Rehabilitation Facilities
5530 Wisconsin Avenue NW, #955
Washington, DC 20015
301-654-5882
Association for medically oriented rehabilitation centers and sheltered workshops. Hosts educational seminars and publishes a newsletter.

National Association of State Directors of Veterans Affairs
State Capitol
Des Moines, IA 50319
515-278-9331
An association for the exchange of ideas and information to ensure equality of service and legislation. Publications are available from this professional organization.

National Association of State Mental Health Program Directors
1001 Third Street, SW, Suite 114
Washington, DC 20024
202-554-7807
An association for the exchange of ideas for public mental health programs Publications are available from this professional organization.

National Center for a Barrier Free Environment
1140 Connecticut Avenue, NW
Room 1006
Washington, DC 20036
202-466-6896
A national information center with a clearinghouse for publications; promotes research and is a membership organization.

National Congress of Organizations of the Physically Handicapped, Inc.
1627 Deborah Avenue
Rockford, IL 61103
815-877-4900
Promotes employment opportunities, legislation, equal rights, social activity and rehabilitation. Publications are available from this professional organization.

PROFESSIONAL ORGANIZATIONS AND ASSOCIATIONS

National Easter Seal Society for Crippled Children and Adults
2033 West Ogden Avenue
Chicago, IL 60612
312-243-8400
Assists people who are disabled and their families in finding and using available resources: vocational, camping, recreational, educational. Publications are available.

National Federation of the Blind
1629 K Street, NW, #701
Office #10
Washington, DC 20006
202-785-2974
A federation for education, assisting victims of discrimination, research, legislation, and scholarships to blind students. Publications are available.

National Foundation of Dentistry for the Handicapped
1726 Champa Street, Suite 422
Denver, CO 80202
303-573-0264
An educational materials dispensary and referral system. This is a professional organization.

National Handicapped Sports and Recreation Association
Capitol Hill Station
P.O. Box 18664
Denver, CO 80218
303-978-0564
An organization to promote sports and recreation: alpine, nordic, water skiing, rafting, kayak, golf, horseback riding, scuba.

The National Hemophilia Foundation
25 West 39th Street
New York, NY 10018
212-869-9740
Promotes research, publishes information, conducts fund-raising, provides scholarships, encourages summer camp programs to provide normal recreation activities. Publishes a newsletter.

National Industries for the Blind
1455 Broad Street
Bloomfield, NJ 07003
201-228-3804
Coordination of workshops for people who are blind; researches new products, and price revisions. Publications are available.

National Mental Health Association
1800 N. Kent Street
Arlington, VA 22209
703-528-6405
Promotes research, social action, education, service, rehabilitation, and community mental health services for adults and children. Publishes a catalog, a professional organization.

National Multiple Sclerosis Society
205 East 42nd Street
New York, NY 10017
212-986-3240
A society for research, fellowships, grants, interested in special clinics within existing hospitals. Publications are available within this professional organization.

National Rehabilitation Association
1522 K. Street, NW
Washington, DC 20005
202-659-2430
An advocacy organization which promotes professional training opportunities, publishes a journal, newsletter, and is a professional organization.

National Rehabilitation Counseling Association
1522 K. Street, NW
Washington, DC 20005
202-296-6080
Interested in developing professional standards, research, and certification. Publications are available from this professional organization.

National Safety Council
425 Michigan Avenue
Chicago, IL 60611
312-527-4800
A clearinghouse and library of accident prevention data, publishes in the area. This is a national organization.

The National Society for Autistic Children
1234 Massachusetts Avenue, NW
Suite 1017
Washington, DC 20005
202-783-0125
A society which advocates, conducts a job exchange for employers in the field, and is a clearinghouse of information and referral services. Publications are available from this professional organization.

National Society for the Prevention of Blindness, Inc.
79 Madison Avenue
New York, NY 10016
212-684-3505
Promotes research, community services, vision screening, professional education and public information. Publications are available.

National Spinal Cord Injury Foundation
369 Elliot Street
Newton Upper Falls, MA 02164
617-964-0521
Promotes research fellowships, develop quality care systems, advocacy, consultation, and improving services for people who are paraplegics.

Paraplegics Manufacturing Co., Inc.
304 North York Road
Bensenville, IL 60106
312-766-0350
Provides employment and sub-contracting to major manufacturers.

Partners of the Americas Rehabilitation Education Program
2001 S. Street, NW
Washington, DC 20009
202-332-7332
Provides a channel between US, Latin America, Carribean nations involved in agricultural development, rural development, community education, health, and rehabilitation services. Publications are available.

Placement & Referral Center for Handicapped Students
Board of Education, New York
362 Schermerhorn Street
Brooklyn, NY 11217
212-624-0854
Provides career counseling, social rehabilitation, job placement and referrals.

The President's Committee on Employment of the Handicapped
1111 20th Street, NW
Washington, DC 20036
202-653-5044
Involved in national education and information programs, training, rehabilitation and employment opportunities. This is a national committee.

President's Committee on Mental Retardation
7th and D Streets, SW
Washington, DC 20201
202-245-7634
Advocates for screening, early intervention and legal rights. Publications are available from this national committee.

Rehabilitation International USA (RIUSA)
20 West 40th Street
New York, NY 10018
212-869-9907
Rehabilitation promotion, information and services, and a film library Publications are available. This is an information dissemination service.

Rehabilitation Services Administration
Department of Education
330 C Street, SW
Washington, DC 20201
202-245-8492
Management of provisions of Rehabilitation Act of 1973, matching funds, program support, guidance.

Society of the Rehabilitation of the Facially Disfigured, Inc.
550 First Avenue
New York, NY 10016
212-679-1534
Provides support of clinical services, training programs, public education and referrals. Publications are available.

United Cerebral Palsy Associations, Inc.
66 East 34th Street
New York, NY 10016
212-481-6300
Professional service programs, research, infant care centers, and adult vocational services. Publications are available.

United Mine Workers of America Health and Retirement Funds
2021 K Street, NW
Washington, DC 20006
202-452-5000
Medical services, vocational, rehabilitation services. Publications are available.

United Ostomy Association, Inc.
1111 Wilshire Blvd.
Los Angeles, CA 90017
213-481-2811
Disseminates information, research, public education. Publications are available from this professional organization.

U.S. Council of the World Veterans Federation
1508 19th Street, NW
Washington, DC 20036
202-232-4000
A clearinghouse for legislation, rehabilitation information.

United States Wheelchair Sports Fund
40-24 62nd Street
Woodside, NY 11377
212-424-2929
Encourages growth of wheelchair sports, aid in sponsoring wheelchair sports. Publications are available, rules, training and techniques for athletics.

The Veterans Administration Dept. of Medicine and Surgery
810 Vermont Avenue, NW
Washington, DC 20420
202-393-4120
Administers programs for medical care, rehabilitation, and education. Publications are available.

Veterans of Foreign Wars of the United States
34th and Broadway
Kansas City, MO 64111
816-756-3390
Rehabilitation, legislation, community activities. Publications are available. This is an organization for veterans.

Welfare of the Blind, Inc.
5647 Bent Branch Road
Washington, DC 20016
301-229-0154
Provides assistance to the sightless of the Third World, supports missionaries and missions in Iran and Togo.

World Rehabilitation Fund, Inc.
400 East 34th Street
New York, NY 10016
212-679-3200
Interested in expanding and improving rehabilitation services to individuals who are physically handicapped, providing training, consultation. Publications are available, membership organization.

ADDITIONAL ENTRIES:

The Legal Resource Center for the Disabled
David Popiel, Esq.
55 Washington Street
East Orange, NJ 07017
Advocacy program providing legal services for disability-related issues. Offers legal counseling and representation, training programs for volunteers and consumers and information on pending laws, rules, and policies affecting individuals with disabilities.

HIP (Help for Incontinent People)
P.O. Box 544
Union, South Carolina 29379
An organization founded in 1983 to assist people who have bladder control problems. Publishes a free quarterly newsletter (The HIP Report); involved in advocacy activities related to improving attitudes, legislation that pertains to insurances issues, products, and communication.

Support Dogs for the Handicapped
P.O. Box 28457
Columbus, OH 43228-0457
A privately funded organization which provides (at no charge) specially trained dogs to people with disabilities and their families. A committee decides eligibility after receiving an initial application from the individual seeking assistance.

The National Organization on Disability
2100 Pennsylvania Avenue, N.W.
Suite 234
Washington, D.C. 20037
A private, non-profit organization concerned with all types of disabilities and the people they affect. Vast network of volunteers in community groups, corporations, national organizations and has liaisons in the fifty states.

TRIPOD
955 North Alfred Street
Los Angeles, CA 90069
HOTLINE: (800) 352-8888 (outside of California)
(800) 346-8888 (in California)
A non-profit organization committed to giving families information about deafness. Created a toll-free hotline (the GRAPEVINE) provide counseling, information and referrals to professionals and resources in the caller's local community.

Travel Information Center
Moss Rehabilitation Hospital
12th Street and Tabor Road
Philadelphia, PA 19141

Muscular Dystrophy Association
810 Seventh Avenue
New York, NY 10019
Supports worldwide research, provides information and special publications pertaining to MD. A national voluntary health agency that coordinates a nationwide network of hospital-affiliated clinics and provides professional and public health education.

National Information Center for Handicapped Children and Youth (NICHCY)
Mr. James Murphy
1555 Wilson Boulevard
Rosslyn, VA 22209
A national clearinghouse sponsored by the U. S. Department of Education; provides publications about specific disabilities, addresses of national, state and local support organizations, resource information, and "how-to" information to parents of children with disabilities, adults with disabilities and professionals working with them.

RECREATION SERVICES

Various agencies throughout Massachusetts provide recreation programs for individuals with disabilities. Some programs are integrated; that is, youngsters and adults with disabilities are included in programs with non-disabled peers. Most agencies, however, only offer programs for groups of people who have similar disabilities.

Every effort has been made to present a complete and up-to-date listing of programs and services. Names of contact people and programs offered are bound to change; therefore, we suggest you call the agency in order to get the most current information.

RECREATION SERVICES

GREATER BOSTON AREA

ARLINGTON

Arlington Recreation
422 Summer Street
Arlington, MA 02143
617-643-6700 x321
After school programs, special olymmpics, summer day program, adult social groups, bowling, dancing, exercise programs, trips. Various fees collected for all programs, ages from 3 and up.

BOSTON

Big Sisters Association
140 Clarendon Street
Boston, MA 02116
617-267-4406
Provides support systems and programs for girls age 7-14.

Boston YMCA
140 Claredon Street
Boston, MA 02216
617-536-7940
Provides aquatics physical education, housing, education, social services; however, accessibility & transportation are limited.

Camp Joy/Boston Parks & Recreation
Room 816, Boston City Hall
Boston, MA 02201
617-725-3469
Services include outings, performing arts, summer camp, seasonal recreational programs for children of all abilities ages 3 and older; occasional fees required, summer transportation available for all.

Don Orione Adult Day Health Center
Lorraine Ware,T.R.S.
111 Orient Ave.
East Boston, MA 02128
617-569-2100
Adult Day Activity Center providing therapeutic recreation.

Ellis Adult Day Center
Mara Wissinger,T.R.S.
44 Chandler St.

Boston, MA 02166
617-426-2727
Adult Day Activity Center providing therapeutic recreation.

Greater Boston Easter Seal Stroke Club
Nancy Drour
934 Statler Office Building
20 Park Plaza
Boston, MA 02116
617-482-3370
Programs in socialization, recreation, education; meets monthly, at the Elliot Church in Newton Center.

Greater Roxbury/South End Easter Seal Stroke Club
Rosiland Fisher
934 Statler Office Building
20 Park Plaza
Boston, MA 02116
617-482-3370
Programs in recreation, socialization, education; meets monthly, at the Harriet Tubman House, Columbus Avenue, Roxbury.

Handicapped Encounter Retreats
Dr. Nancy Mehlem
28B Fleet St
Boston, MA 02113
617-367-3664
Services include performing arts and a "retreat experience"; donations accepted; services for people of all abilities.

The Massachusetts Division of Tourism
Massachusetts Department of Commerce and Development
Box 1777
Boston, MA 02105
617-727-3201
Provides information on accessible camp grounds throughout the state.

The Massachusetts Special Olympics
Statler Office Bldg, Suite #524
20 Providence Street
Boston, MA 02116
617-451-5747
Provides a statewide program of sports training and competition for participants with mental retardation.

Metropolitan District Commission
20 Somerset Street
Boston, MA 02108
617-727-9547

Provides recreational facilities and services needs of 37 cities and that make up the MDC Parks and Recreation division; associated with Annual Summerfest celebrations.

Moray Wheel's Adaptive Scuba Association
John Nelson
P.O. Box 1660, General Mail Facility
Boston, MA 02205
617-426-2463
A sports club dedicated to promoting scuba diving among people with disabilitiee.

New England Handicapped Sportsmen's Association
P.O. Box 2150
Boston, MA 02106
617-367-8847
Provides adaptive sports instruction and opportunities for participation in winter skiing, sailing, water skiing, scuba diving and canoeing for persons who are amputees, post polio, blind, Cerebal Palsied and/or with congenital deformities.

Para Tours, Inc.
Donald S. Gagne
698 Beacon Street
Boston, MA 02215
617-247-2533
Provides a 3-hour ride of individual's choice within a reasonable distance of Boston. Services are for people of all ages and disabilities including those persons who are bedridden or confined to nursing homes.

Patriots Trail Girl Scout Council, Inc.
Pat McCabe
6 St. James Avenue
Boston, MA 02116
617-482-1078
Programs in music, dance, crafts, camping trips, boating, independent living skills, computer, animal care, woodworking. Participants must be registered members of GSA.

School Volunteers for Boston, Inc.
138 Tremont Street
Boston, MA 02111
617-267-2626 or 617-451-6145
Provides educational assistance, outings, volunteer training programs, "sensitivity" program for non-disabled students and volunteer placements.

South Boston Area Easter Seal Stroke Club
Bea Reynolds
934 Statler Office Building

20 Park Plaza
Boston, MA 02116
617-482-3370
Provides recreation, socialization, and education; meets monthly at the John Powers Apartments, South Boston.

Suffolk County Special Olympics
Leisure Studies Program
Boston University
605 Commonwealth Avenue
Boston, MA 02215
617-353-4226
Events include aquatics, bowling, track & field, sports clinic; transportation occasionally coordinated.

Thompson Island Education Center
Thompson's Island
Boston, MA 02127
617-328-3900
Outdoor and indoor classroom/education/recreation; accessible by boat only; for youth and adults.

Young Adult Fellowship
Rosiland Fisher
934 Statler Office Building
20 Park Plaza
Boston, MA 02116
617-482-3370
Provides education, recreation, and socialization for stroke and head injured persons 15-25 years; meets monthly.

BRIGHTON, BROOKLINE

Mohawks and Squaws
50 Sutherland Rd
Brighton, MA 02135
617-566-8799, 617-782-2045
Social club meetings every Tuesday night at 7:30; membership fee; for persons with mental retardation who are 18 years or older.

The Therapeutic Center
Carmine Alfieri
16 Hurd Road
Brookline, MA 02146
617-566-1443
Provides opportunities for dance, drawing, camping, exercise, independent living skills, games, sports, social/cultural trips health care. Transportation is provided under Chapter 766. Also educational and therapeutic day programs for persons ages 5 - 15 and a day camp for children with emotional disturbances.

Some fees required for certain programs.

CAMBRIDGE, SOMMERVILLE

Cambridge Camping Association, Inc.
99 Bishop Richard Allen Drive
Cambridge, MA 02139
617-864-0960
Summer and fall camping programs and referral; services for people with a range of disabilities. Eight week summer program; Fall Programs - Saturdays for 10 weeks

Easter Seal Stroke Club for Somerville/Cambridge
Rosiland Fisher
934 Statler Office Building
20 Park Plaza
Boston, MA 02116
617-482-3370
Provides recreation, education, and socialization; meets monthly at the Somerville/Cambridge Elder Services.

The New England Center for Recreational Therapy
152 Prospect Street
Cambridge, MA 02139
617-547-2760
Rents camp facility to agencies that deal with people with disabilities or who are underprivileged. Provides help with program planning, waterfront activities, indoor crafts, winter sports

Young Women's Christian Association of Cambridge
Central Square
Cambridge, MA 02139
617-491-6050
Physical recreation, educational courses for men and women; At this writing adapted aquatics is the only program for people with developmental disabilities.

CHICOPEE, DEDHAM

Pioneer Developmental Center, Inc.
12 Fairview Avenue
Chicopee, MA 01013
413-549-9141
Provides family respite, resource services, community recreation, and training and support to generic agencies. Six recrea-

tion programs are held in the community.

Dedham Park and Recreation Department
Town Hall Building
Dedham, MA 02026
617-326-3322
Provides physical recreation & performing arts to children through age 21: Dedham residents only Also provides an 8-wk summer playground with transportation and a Friday night program without transportation.

Toward Independent Living & Learning, Inc
515 Providence Highway
Dedham, MA 02026
617-329-6150
Provides support, training, residential and day programs, recreation and a monthly newsletter. Has a variety of social programs for persons of all ages whose primary disibility is mental retardation.

DORCHESTER, MATTAPAN

Lena Park Community Development Corporation
150 American Legion Highway
Dorchester, MA 02124
617-436-1900
Provides a community residence, social services, and advocacy services. Clientele must be DMH clients and at least 18; priority is given to Dorchester and Mattapan residents.

Kit Clarke Senior House
Laurie Loftus
1500 Dorchester Ave.
Dorchester, MA 02122
617-825-5000
Adult Day Activity Center providing therapeutic recreation.

MALDEN, MEDFORD, MELROSE

Indoor Sports Club, Inc.
Dorotyh A. McNeil
34 Dana Street
Malden, MA 02148
617-322-9308
Provides monthly social programs for individuals with physical disabilities; small fee required.

Hegner Center, Inc.
Colleen McKenna
1015 Maple Park Avenue
Medford, MA 02155
617-395-1156
Provides a drop-in center for individuals aged 22 and over. Includes travle clubs, cooking, exercise, aquatics, team sports.

East Middlesex Association for Retarded Citizens
Joan Cassidy
663 Main Street
Melrose, MA 02176
617-662-6371
Provides a summer program for children ages 5 - 14; services include art and speech and language therapy, aquatics, trips; fee required.

NEWTON

Charles River Canoe Service
Larry Smith
2401 Commonwealth Avenue
Newton, MA 02166
617-965-5110
Canoeing - instruction, day trips, overnight trips; also offers skiing in the winter at Weston Ski Track.

Carroll Center for the Blind
Arthur O'Neil
770 Centre Street
Newton, MA 02158
1-800-852-3131
Provides recreation program for persons with visual impairments (skating, skiing, hiking, biking, sailing, some overnight trips); fee required.

Family Counseling Service - Region West
Roberta Jaro
74 Walnut Park
Newton Corner, MA 02158
617-965-6200
Programs include cook-outs, independent living skills, frisbee, movies, dances, social events, games, music, painting, excercise. Wednesday evening drop-in center, 7 - 9 PM.

League School of Boston, Inc.
Christine Brumbach
225 Nevada Street
Newtonville, MA 02160

617-964-3260
This psychoeducational institution offers a summer program. Call for more information.

Leventhal-Sidman Jewish Community Center
Anncharlene Dresner
333 Nahanton Street
Newton, MA 02159
617-965-7410
Programs include music, drama, painting, crafts, excercise, first aid, theater, concerts, travel, social events, team sports, swimming. The Center is a non-profit social service agency.

Little People's/Learning Prep School
Karen Jacobs
1507 Washington Street
West Newton, MA 02165
617-965-0764
Programs include dance, painting, photography, ceramics, hiking, camping trips, picnics, horticulture, bowling, sports, crafts.

Massachusetts Cerebral Palsy of Greater Boston
Edith P. Schneider
515 Centre Street
Newton, MA 02158
617-969-3214
Programs include music, camping, gardening, exercise, life skills, dances, baseball, weaving, cook-outs. Also offers a summer program in conjunction with Newton Recreation Department.

Newton Parks and Recreation Department, Special Needs Programs
Karen Flannery
70 Crescent Street
Auburndale, MA 02166
617-552-7120
Programs include dance, music, clowning, crafts, summer day camp, boating, excercise, nature studies, woodworking, day trips, sports, swimming; also offers a drop-in center on first Saturday of each month.

Newton YMCA Youth Department
Michael T. Kozul
276 Church Street
Newton, MA 02158
617-244-6050
Programs include dance, summer day camp, hiking, crafts, excercise, sports, swimming, self defense; also an eight-week pottery/ceramics course for adults with special needs.

NORTH OF BOSTON

ANDOVER

Andover Department of Community Services
Mary Donahue
Shawsheen School
Ann's Lane
Andover, MA 01810
617-475-5045
Provides special education, summer playground, sports, physical activities, trips, adult education,money management, dance, exercises. Transportation for summer playground only; varied fees; ages, 3+.

Greater Lawrence Educational Collaborative
10 High Street
Andover, MA 01810
617-460-1990
Camp program, field trips, cook outs, environmental education. Summer camp program: swimming, boating, nature walks. Transportation provided from DMH; Lunch is free if child is eligible during school year.

Greater Lawrence Educational Collaborative/Camp Stepping Stone
Bernice Pierce
c/o 10 High Street
Andover, MA 01810
617-470-1990
Summer Camp, aquatics, boating, nature, music, trips for children ages 3 1/2 - 21; fees varied for 4 or 6 week program.

BEVERLY

Beverly Regional YMCA
Joan Sutherland
245 Cabot Street
Beverly, MA 01915
617-922-0990
Services include aquatics, physical education, performing arts, summer camp, fee, pool, gym, weight room; shower & locker room are accessible.

New England Aquatics, Inc.
PO Box 652, Brimball Avenue
Beverly, MA 01915
617-922-4008

PEP: RECREATION SERVICES

Services include aquatics, recreational and free swim, special olympic team, jacuzzi for people of all abilities and ages,

BURLINGTON

Burlington Community Life Center
Armand Henault
Center School
Center Street
Burlington, MA 01803
617-273-1300
Activity therapy groups for persons with learning disabilities.

Burlington Recreation Department
Don Roberts
Town Hall
Burlington, MA 01803
617-272-7330
Programs in dance, drawing, photography, exercise, sports, games, day trips, computer, first aid, cooking and Special Olympics Also has a February and April vacation program and a special event called, the "Celebrate Program."

Burnham Center
Lynn Andrews
48 Winn Street
Burlington, MA 01803
617-273-0727 or 944-7798
Programs in music, dance, drama, ceramics, exercise, weaving, nutrition, first aid, cooking, day trips. Also, four 8-week sessions of adult education classes ($30 fee).

EVERETT

Everett Day Activity Center
407 Main Street
Everett, MA 02149
617-389-3206
Programs focus on pre-vocational, communication, socialization, acedemics, use of leisure time, recreation, primarily for persons who are moderately to severely retarded; Hours typically M-F 9am-3pm with recreation programs weekly and monthly for persons over age 16.

HAMILTON

Hamilton Recreation Department
Richard A. Vitale
Town Hall
Hamilton, MA 01936

617-468-4455
Provides summer playground activities and aqautics programs for people who are physically disabled or mentally reatrded; fee required.

HAVERHILL

Haverhill Recreation Department
Robert H. Cox
10 Welcome Street
Haverhill. MA 01830
617-373-4897
Provides summer progrrams for youngsters ages 6-21 who are mentally reatrded or physically disabled.

Northern Essex County ARC
4 Summer Street, Room 6
Haverhill, MA 01830
617-373-0552
Programs include recreation, social and educational opportunities for people with developmental disabilities of all ages; transportation is provided for summer only.

IPSWICH

Ipswich Recreation Department
Elizabeth Dorman
23 Central Street
Ipswich, MA 01938
617-356-3767
Provides a Saturday program for individuals (ages 6-30) who are mentally retarded or who have muscular dystrophy.

LAWRENCE

Citizen's League for Adult Special Services (CLASS, Inc.)
Sharon Cores
447 Essex Street
Lawrence, MA 01840
617-688-5109
Provides various types of services and programs (ADL, functional academics, pre-voc, workshop, language and community skill development) for individuals aged 22+ who are mentally reatrded, have cerebral palsy, or who are blind or deaf.

Easter Seal Society
20 Ballard Road
Lawrence, MA 01843
617-683-1259
Serves children (6 months +) and adults with CP, Spina Bifida, various birth anomolies, or victims of traumatic injury.

Programs include camping, aquatics, horseback riding, bowling, etc.

Northeast Independent Living Program, Inc.
429 Brpoadway
Lawrence, MA 01840
617-687-4288
Provides recreation programs for individuals (18+) who have severe physical disabilities.

LOWELL

ARC of Greater Lowell, Inc.
145 Lexington Avenue
Lowell, MA 01851
For youngsters (10+) and adults who are mentally retarded; programs in games, dances, bowling skiing, aquatics, special events, sports clinics, etc.

Cape Ann YMCA
71 Middle Street
Lowell, MA 01851
617-283-0470
Serves individuals with various disabilities, ages 7 through adult; programs in aquatics, gym, weight lifting.

Greater Lowell Family YMCA
45 YMCA Drive
Lowell, MA 01851
617-565-8936
Aquatic programs only; for children and adults (7+) with physical or mental disabilities.

Lowell Association for the Blind
201 Thorndike Street
Lowell, MA 01824
617-454-5704
Serves people who are blind (all ages); programs include trips, entertainment, picnics, arts, bowling, etc.

Lowell Recreation Department
J.F.K. Civic Center
50 Arcand Drive
Lowell, MA 01851
617-454-8821, x281
Provides a variety of recreation programs -- check with the department to ascertain which are accessible to individuals with disabilities.

Renaissance Pre-Vocational and Social Program
21 Branch treet
Lowell, MA 01851
617-454-7944
Provides a variety of recreation programs for individuals with

psychiatric disabilities; fee required.

LYNN

Camp Kiwanis
21 Oakville Street
Lynn, MA 01905
617-598-8870; 593-3610
Provides a variety of programs for children ages 3+; follows a school-year schedule.

Greater Lynn Mental Health and Retardation Association
56 Baltimore Street
Lynn, MA 01905
617-593-1088 or 1089
Provides a variety of recreation and other types of services.

United Cerebral Palsy Assoc. of the North Shore
103 Johnson Street
Lynn, MA 01902
617-593-2720
Provides a variety of recreation programs for individuals with cerebral palsy or with physical disabilities who are 18 years of age or older.

MARBLEHEAD

Marblehead Recreation and Park Commission
Marblehead, MA 01945
617-631-3350
Provides a variety of recreation services and programs including summer activities such as fishing, games, crafts, trips; also self-help skill development programs; open to all.

Marblehead/Swampscott YMCA
104 Pleasant Street
Marblehead, MA 01945
617-631-0870
Swimming pool has a lift which makes it accessible to people with physical disabilities and mobility impairments.

METHUEN

Nevin's Adult Day Health Center
110 Broadway
Methuen, MA 01844
617-686-2807
For people age 16+, programs in arts, crafts, trips, bowling, movies, parties; also health care programs. Fee is paid by Medicaid and the Commission for the Blind.

PEABODY

City of Peabody Recreation, Parks & Forestry Department
Richard P. Walker
Perkins Street
Peabody, MA 01960
617-531-8427
Provides a seven-week day camp for children and young adults (4-22) who are mentally retarded or emotionally disturbed.

REVERE

Revere Parks and Recreation Department
Helen Papa
150 Branch Street
Revere, MA 02151
617-283-3360
For individuals ages 6+ with mental retardation or physical disability; provides both summer and year-round recreation programs.

SALEM

North Shore Association for Retarded Citizens, Inc.
Terry Bernardo
184 Lafayette Street
Salem, MA 01970
617-744-1225
Recreation programs of all types for individuals (all ages) who are mentally retarded.

Salem Recreation Department
3 Broad Street
Salem, MA 01970
617-744-0733
Provides a summer program for people of all ages who are mentally retarded or physically disabled.

WAKEFIELD

Wakefield YMCA
317 Main Street
Wakefield, MA 01880
617-245-9622
Programs for individuals (6-30) with learning disabilities, mental retardation or physical disabilities.

WOBURN

Woburn Easter Seal Stroke Club
c/o Rosiland Fisher
934 Statler Office Building
20 Park Plaza
Boston, MA 02116
617-482-3370
Provides recreation, education, socialization. Holds monthly meetings at Woburn Senior Center.

North Suburban YMCA
137 Lexington Street
Woburn, MA 01801
617-935-3270
Provides a variety of recreation and sports programs for people ages 3 to adult; also has fitness programs and facilities for people 18+; serves all people; fees required.

SOUTH OF BOSTON

ATTLEBORO

Greater Attleboro Easter Seal Stroke Club
Judy Adams
Sturdy Memorial Hospital
Attleboro, MA 02703
617-222-5200, ext. 3243
Provides recreation, socialization, education; meets monthly.

BRAINTREE

Braintree Rehabilitation Hospital
350 Pond Street
Braintree, Massachusetts 02184
Provides in-patient and out-patient therapeutic recreation and leisure education programs primarily for people with head injury and other physical disabilities.

Braintree Park Department
Bill Hedlund
Union Street
Braintree, MA 02184
617-843-8442/0739
Has a golf course, park facilities, school athletic facilities, two waterfronts, special needs summer day program, playground activities; various seasonal activities for all; transportation for summer only.

Disabled American Veterans
Warren Driscoll
788 Librerty Street
Braintree, MA 02184
617-843-9688 (Tuesday afternoons only)
Has function halls available for 50-250 people; wheelchair accessible.

Human Services Resource Center - Braintree Day Hab. Program
Barry Drangel
30 Foster Road
Braintree, MA 02184
617-848-6466
Programs focus on independent living skills, nutrition, day trips, social events. All emphasize pre-vocational skills, recreation, job-readiness skills.

Therapeutic Community, Inc., Day Habilitation
Jane Cawley
482 Washington St.
Braintree, MA 02184
617-848-4052
Programs in independent living skills, health care, day trips, bowling, basketball. Clients must have a developmental disability and be Medicaid recipients.

BRIDGEWATER

Handi-Kids
Patti Phillips
470 Pine Street
Bridgewater, MA 02324
617-697-7557
Programs in dance, drama, crafts, summer day camp, aerobics, cooking, games, theater, day trips, swimming, horseback riding, team sports

BROCKTON

Greater Brockton Easter Seal Stroke Club
Barbara McGrath
Brockton Hospital
680 Centre Street
Brockton, MA 02402
617-586-2600
Provides socialization, recreation, and education; meets monthly at the Brockton Multi-Service Center.

Old Colony YMCA
Elaine D´Angelo; Mike MacAdam
320 Main Street
Brockton, MA 02401
617-583-2155
Provides swimming opportunities.

QUINCY

South Shore Stroke Club
Sidney Winders
80 Clay Street
Quincy, MA 02169
617-337-5558
Provides education, socialization, recreation opportunities and a support club for stroke-disabled persons, families and friends.

NEW BEDFORD, FALL RIVER

Cape Cod Easter Seal Stroke Club
1145 Purchase Street
New Bedford, MA 02740
617-997-1553
Provides recreation, socialization, education; meets monthly at the D-Y Senior Center, South Yarmouth.

Greater Fall River Easter Seal Stroke Club
1145 Purchase Street
New Bedford, MA 02740
617-997-1553
Provides recreation, education, socialization; meets monthly at the Somerset Library.

Greater New Bedford Easter Seal Stroke Club
1145 Purchase Street
New Bedford, MA 02740
617-997-1553
Provides recreation, education, socialization; meets monthly at Brandon Woods, South Dartmouth.

Greater Taunton Easter Seal Stroke Club
Phyllis Rubin
1145 Purchase Street
New Bedford, MA 02740
617-997-1553
Provides socialization, recreation, education; meets monthly at the Wedgemere Convalescent Home.

NORWELL

North River Easter Seal Stroke Club
Bea Reynolds
935 Statler Office Building
20 Park Plaza
Boston, MA 02116
617-482-3370
Provides recreation, education, socialization; monthly meetings, at the Norwell Council on Aging.

Norwell Recreation Department
Dale Connor
365 South Street
Norwell, MA 02061
617-659-7227
Programs include dance, camping, painting, sewing, hiking, music, first aid, bowling, sports, cook-outs, horse-back riding, and skating. Preference given to Norwell residents.

NORWOOD

Norfolk Day Activity Center
Linda Hale
50 Central Street
Norwood, MA 02062
617-769-4495
Programs include music, ceramics, painting, needlework, woodworking, movies, social events, bowling, table games, health care. Primarily serves clients over 60 years old, living in or near Norwood.

PLYMOUTH

Greater Plymouth ARC
Carole A. Tagg
Pembroke Community Center
Pembroke, MA 02359
617-294-8100
Provides programs in performing arts, physical education, aquatics, outings and social recreation. Some require fees, and some activities may not be accessible.

WEST OF BOSTON

AMHERST

Amherst Adult Day Center
150 University Drive
Amherst, MA 01002
413-256 8185
Provides counseling, nursing services, nutrition services, speech, physical and respiratory therapy, socialization and education. A viable alternative to institutional living, fully integrated.

FRAMINGHAM

A & A Adaptive Driving Program
Mark Whitehouse
149 Concord Street
Framingham, MA 01701
617-875-1357
Provides evaluation, instructions and recommendations for vehicle modification for persons 16+; holds a contract with Mass. Rehabilitation; fee required.

Framingham Park and Recreation Department
475 Union Avenue
Framingham, MA 01701
617-872-5400
Operates a summer day camp and an after school program for 10 weeks in Winter. Services are for children with special needs who are toilet trained. Transportation provided for Framingham area only.

GREENFIELD

Franklin County ARC
213 Silver Street
Greenfield, MA 01301
413-773-37748
Provides information and referral, residential services, advocacy, and recreation for children or adults who are mentally retarded in Franklin County only. Residential services are DMH referred.

WESTFIELD

Association for the Support of Human Services, Inc.
Judy Hoyt, Director

PEP: RECREATION SERVICES

138 East Mountain Road
Westfield, MA 01085
413-562-5678
A private, not-for-profit organization dedicated to integration of able and disabled persons; includes programs for parents and families; sponsors the Community Enrichment Project, the Family Enhancement Project, Kamp for Kids, Senior Enhancement Center, and Specialized Day Program for adults.

WOODVILLE

New England Wheelchair Athletic Association
Don Milani
P.O. Box 62
Woodville, MA 01784
617-782-6800
Wheelchair athletic games held year-round; practice on an individual basis; sponsors regional wheelchair games; fee required.

WORCESTER, FITCHBURG

South Middlesex Easter Seal Stroke Club
c/o 30 Highland Street
Worcester, MA 01609
617-757-4464
Provides recreation, education, socialization; meets monthly at the Callahan Center in Framingham.

North Worcester County ARC
Charles Forcier, Jr.
558 Main Street
Fitchburg, MA 01420
617-343-6662
Provides advocacy, and a rehabilitation work center; also recreation and social activities as well as special activities for clients with mental retardation, all ages.

North Worcester County Special Olympics
558 Main Street
Fitchburg, MA 01420
617-3443-6662
Facilitates state and national special olympics program coordination for children and adults who are mentally retarded from North Worcester County only.

SPECIAL RECREATION SERVICES

(NOTE: See also previous listings in particular towns and cities.)

Environment Camp for Handicapped and Others (E.C.H.O.)
Frank Robinson
Northeastern University
360 Huntington Avenue
Boston, MA 02115
617-437-3163
Summer and winter camps for children who are disabled and able-bodied; program is held in conjunction with a camping/outdoor education undergraduate course.

Fenway Project
Department of Health, Sport & Leisure Studies
Northeastern University
360 Huntington Avenue
Boston, MA 02115
617-4366-3163/3150
Provides aquatics, companion program, and recreational opportunities for residents of the Fenway; all abilities.

Suffolk County Special Olympics
c/o Leisure Studies Program
Boston University
605 Commonwealth Avenue
Boston, MA 02215
617-353-4226
Programs in aquatics, bowling, track and field, sports clinics; transportation occasionally coordinated.

NATIONAL SPORTS AND SPECIALTY ASSOCIATIONS

Accent on Information, Inc.
Raymond C. Cheever
P.O. Box 700
Bloomington, IL 61701
309-378-2961
Computer search services; leisure, education, etc. Provides publications such as buyer's guides; information on clothing and other daily living necessities as well as information on disability challenges, sexuality, etc.

American Athletic Association of the Deaf
3916 Lantern Drive
Silver Spring, MD 20902
301-942-4042
The national organization dedicated to promoting opportunities for participation in athletics by persons who are deaf and/or hearing impaired.

American Blind Bowling Association
150 North Bellaire Avenue
Lousville, KY 40206
502-896-8039
An association dedicated to promoting bowling as a life-long sport for persons who are blind and/or visually impaired. Provides information and resource referral pertaining to adaptive equipment.

American Camping Association
5040 SR 67 North
Bradford Woods
Martinville, IN 46151
317-342-8456
ACA provides information about camping for all persons.

American National Red Cross
17th and D Streets, NW
Washington, DC 20006
202-857-3542
Noted for adapted aquatics programs and instructor training. Also provides training in CPR and Life Saving through its regional offices.

American Wheelchair Association
2635 N.E. 19th Street
Pompano Beach, FL 33062

305-941-1238
The Wheelchair Association is dedicated to promoting athletic competition among persons who use wheelchairs.

Association of Handicapped Artists
1034 Rand Building
Buffalo, NY 14203
716-853-2660
Dedicated to promoting opportunities for artistic expression and showings of products created by persons with disabilities.

Blind Outdoor Leisure Development
533 East Main Street
Aspen, CO 81611
303-925-8922
Dedicated to promoting outdoor opportunities for leisure among persons who are blind and/or visually impaired.

Boy Scouts of America Scouting for the Handicapped Division
Downing B. Jenks
Boy Scouts of America
P.O. Box 61030
Dallas/Ft. Worth Airport, TX 75261
214-659-2000
Promotes opportunities for scouting with peers; camping, civic activities, crafts. Publications available.

Camp Fire Girls, Inc.
1740 Broadway
New York, NY 10019
212-581-0500

Girl Scouts of America
Scouting Program for the Handicapped
830 Third Avenue
New York, NY 10022
(See, Boy Scouts, above.)

Joseph Bulova School of Watchmaking
Harry B. Henshel
40-24 62nd Street
Woodside, NY 11377
212-424-2929
A vocational rehabilitation center; also provides programs in fitness, swimming; catalogue available.

National Wheelchair Athletic Association
G. Andrew Fleming, Executive Director
2107 Templeton Gap Road, Suite C
Colorado Springs, CO 80907

303-632-0698
Dedicated to sports participation by athletes with disabilities; offer top competition in events such as track and field, swimming and weight lifting. All competitions are conducted according to the athlete's degree of disability. Minimal fee required to become a member.

National Wheelchair Basketball Association
Stan Labanovich, Ph.D., Commissioner
110 Seaton Building
University of Kentucky
Lexington, KY 40506
606-257-1623
Founded in 1949, this organization prints an annual directory and rules book, weekly publication of a newsletter and standings and statistics report of its over 120 basketball teams nationwide. Also provide all forms and information for teams to become registered.

National Wheelchair Softball Association
David C. VanBuskirk, Commissioner
P.O. Box 737
Sioux Falls, ND 57101
605-334-0000
Dedicated to promoting softball competition opportunities for people with disabilities.

Wheelchair Motorcycle Association
c/o Dr. Eli Factor
101 Torrey Street
Brockton, MA 02401
Contact the association for information about modified equipment and membership in the Association dedicated to making this sport accessible to all who want to participate.

Wheelchair Pilots Association
c/o 11018 102nd Avenue North
Largo, FL 33540
This organization holds fly-ins as well as meetings; publishes a monthly newsletter; sells hand controls and a fold away boarding seat and provides information about medical certificates, aircraft for people with disabilities, and instructors.

NATIONAL TRAVEL SERVICES

Ability Tours
719 Delaware Avenue, S.W.
Washington, DC 20024
202-554-9068

Accent on Information
Cillum Road and High Drive
P.O.Box 700
Bloomington, IL 61701
309-378-4213

Adventures in Movement for the Handicapped
945 Danbury Road
Dayton, OH 45420
513-294-4611

Evergreen Travel Service
19429 44th Street, West
Lynnwood, WA 98036
206-776-1184

Flying Wheels Tours
143 W.Bridge Street
P.O. Box 382
Owatonna, MN 55060
507-451-5005

Handy-Cap Horizons
3250 E. Loretta Drive
Indianapolis, IN 46227
317-784-5777

Mobility International U.S.A. (MIUSA)
P.O. Box 3551
Eugene, OR 97403
503-343-1284

Moss Rehabilitation Hospital
12th Street and Tabor Road
Philadelphia, PA 19141
215-329-5715
Maintains an information service for travelers who are disabled.

Society for Advancement of Travel for the Handicapped
26 Court Street
Brooklyn, NY 11242

NOTE: Contacting the Chambers of Commerce in particular cities should provide you with a lot of helpful information regarding accessible travel sites. The National Easter Seal Society can also be very helpful for the traveler using a wheelchair. Write to:

The National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612

The following organizations provide additional information on national and international travel:

The Women's Committee
President's Committee on Employment of the Handicapped
Washington, DC 20210
Publishes a booklet entitled, A List of Guidebooks for Handicapped Travelers which lists the guidebooks of 85 cities in the U.S. as well as those of cities in Canada, Australia, and Europe.
Also available form the President's Committee is a list of highway rest areas that are accessible. Ask for booklet entitled, Highway Rest Area Facilities Designed for Handicapped Travelers. Both publications are free of charge.

U. S. Government Printing Office
Washington, DC 20402
Provides a pamphlet entitled, National Park Guide for the Handicapped. Lists well over 200 areas in the National Park System that are accessible to wheelchair users and those that are accessible to individuals who are blind or deaf. Small fee for this booklet to cover postage and handling.

National Easter Seal Society
2023 West Ogden Avenue
Chicago, IL 60612
Provides a booklet that lists motels that have units accessible to the traveler in a wheelchair.

Great strides have been made during the last decade in improving the accessibility of a number of major motel and hotel chains.

Still your best bet, however, is to call ahead and make sure the facility you are considering is accessible, or write to corporate headquarters. Some of the major chains are listed below.

TRAVEL SERVICES

Best Western, Inc.
2910 Sky Harbor Boulevard
Phoenix, AZ 85034

Holiday Inn, Inc.
3742 Lamar Avenue
Memphis, TN 38118

Howard Johnson's
222 Forbes Road
Braintree, MA 02184

Ramada Inns, Inc.
P.O. Box 590
Dept. RW
Phoenix, AZ 85001

Rodeway Inns of America
P.O. Box 34736
Dallas, TX 75234

WORKSHEETS

In this section of the PEP, the reader will find several worksheets that have been designed to assist in the empowerment process. They have been arranged in the following order:

- Primary Contacts
- The Telephone Log
- Positive Contacts
- Our Family's Problem-Solving Worksheet
- Our Family's Action Plan
- Film and the Family

THE PRIMARY CONTACT LIST

Patricia A. Shank, Ph.D.

Once a child with one or more disabilities is introduced into the family system, the immediate support system will broaden to include professionals and significant others with varied expertise. The PRIMARY CONATCT LIST is an instrument that can be used and regarded as a working document for the entire family. It will be most helpful if placed in a conspicuous spot near the phone.

SUGGESTIONS FOR USING THE LIST:

1. Our immediate suggestion is to write your key names and addresses in pencil, for they're bound to change. Pencil use is also suggested as a subtle reminder that your choices regarding who becomes a part of your support network may change. For example, the doctor who was recommended by a friend may not be the right one for your child. Or the practitioner who insists on maintaining a condescending attitude when speaking to you should surely get the erasure as should anyone whose handicappist attitudes are detrimental to you or your child's personhood.

   There will be times, naturally, when you won't have the luxury of erasing the name of someone who is particularly difficult to deal with. There might not be a more pleasant substitute available due to the role or nature of that person's position. In those cases, jot yourself a note in the COLUMN section to call that person if possible only when you are well-rested and feeling most assertive.

2. Jot down the particular SPECIALTY of the primary contact person. You might have all the essential information in your head, but other family members or respite care providers might not.

3. Anything that could interfere with your contacting the person should be included in the COMMENTS section. For example, the Physical Therapist may have Sundays and Mondays off, your favorite babysitter may have team practice twice a week until 7 P.M., or your physician may have limited hours on certain days.

Primary Contacts List

	NAME	ADDRESS	PHONE	SPECIALTY	COMMENTS
PHYSICIANS					
THERAPISTS/ PRACTITIONERS					
HOSPITAL PERSONNEL					
EDUCATION PERSONNEL					
RESPITE CARE PROVIDERS/ BABYSITTERS					
AGENCIES/ ORGANIZATIONS					

Primary Contacts List

	NAME	ADDRESS	PHONE	SPECIALTY	COMMENTS

Primary Contacts List

	NAME	ADDRESS	PHONE	SPECIALTY	COMMENTS

Telephone log

Patricia A. Shank, Ph.D.

Telephoning for some people is uncomfortable and a cause of distress. As a result, many of our phone calls may leave us frustrated and without the information we wanted in the first place unless we give ourselves some coping strategies to follow. The TELEPHONE LOG was designed in part as an aid in developing those strategies.

Self-empowerment suggests the need to seek out information judiciously. In order to find what it is we are looking for, we need to know how to question appropriately. And once we've found some answers, we need to know what to do with them, that is, to identify the next step to be taken. The TELEPHONE LOG enables the us to formulate questions before making a phone call, to keep track of who we called, when we called and what we called about, and to record any action required for follow-up (the next step).

SUGGESTIONS FOR USING THE LOG:

1. Before you pick up the phone, write down the date, the agency or specific person you intend to call and the phone number you will be using.
2. Go to the column entitled, ISSUE, and write down the general category(ies) your question pertains to.
   For example, you intend to call the school principal for the purpose of clarifying something on your child's Individual Education Plan (IEP). Under the ISSUE column, write IEP - 3/25/87.

3. Next, go to the column entitled, SPECIFIC QUESTIONS. Write down as specifically as possible the question(s) you have.

   For example,

ISSUE	SPECIFIC QUESTIONS
IEP - 3/25/87	o Can I change my mind about my child's placement after I've already signed my acceptance of the IEP? o Can I come to the IEP meeting with suggestions for specific goals I feel should be included in the plan? o Can I bring someone with me to the IEP meeting who knows special education procedures [or who works with my child, etc.]?

4. Make the phone call. Jot down the name (and title if appropriate) of the person you actually did talk to. On some occasions, there might be a number of persons you have to go through before you get to the person who can actually help you -- write them all down for your "track" record.

5. Next, write down the answers you got to your questions in the column entitled, RESPONSE(S) REC'D. Any "next step" actions should then be recorded in the column entitled, ACTIONS REQUIRED.

Telephone log

DATE	AGENCY/PERSON CONTACTED	PHONE #	NAME/TITLE OF PERSON TALKED TO	ISSUE	SPECIFIC QUESTIONS	RESPONSE REC'D.	ACTION REQUIRED

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Telephone log

DATE	AGENCY/PERSON CONTACTED	PHONE #	NAME/TITLE OF PERSON TALKED TO	ISSUE	SPECIFIC QUESTIONS	RESPONSE REC'D.	ACTION REQUIRED

POSITIVE CONTACTS

Patricia A. Shank, Ph. D.

From time to time, we meet people who genuinely care about us. They may be particularly warm and caring or they may REALLY listen to us and therefore, hear what it is we might be struggling to say. Once in awhile we might interact with a secretary or a janitor or a "front line" person who seems to know more than anyone else in a bureaucratic maze. These are positive contacts. Holding on to the encounter may be particularly helpful during times when it seems nobody hears or sees us. There may also be times when the possibility of future contacts with the person is real and important, so we want to be sure we'll know how to contact them.

The POSITIVE CONTACTS MADE list was designed with these thoughts in mind. You might want to use the form to record -- journal style -- a summary of a positive contact you have had. Or you might want to jot down the name and phone number of helpful, knowledgeable therapists, secretaries, janitors or teachers -- anyone whose interactions with you indicate that they value you as a person.

Positive Contacts

DATE	NAME OF PERSON	TELEPHONE #	AFFILIATION & ADDRESS	SUMMARY OF ENCOUNTER

Our Problem Solving Worksheet

Patricia A. Shank, Ph.D.

"I can't see the forest for the trees." "I get in my own way." "We think differently." "I don't know where to start."

Most likely, we've all said one or more of the above statements at one time or another. Understandable feelings, but not real helpful when we need to come to some decision or realize that we need to move ahead instead of standing still. Problem solving is the process of resolving unsettled matters or finding a workable solution to some difficulty we are experiencing.

What constitutes a problem for one person may not necessarily be the same for another person, for problems are matters of perception. Basically, a problem is a discrepancy or difference in what I perceive actually is and what I want it to be.

SUGGESTIONS FOR USE OF THE PROBLEM SOLVING WORKSHEET

1. There are essentially five basic steps in the problem-solving process: (a) defining the problem, (2) diagnosing its causes and the issues involved, (c) formulating strategies or alternatives for solving it, (d) deciding from among the solution alternatives and implementing the chosen alternative, and (e) evaluating the success of the strategy used. Each of the steps is interrelated and dependent upon how specific we have been at each step.

2. The clearer and more accurate we have been in defining the problem, the easier it will be to complete the other steps. What is the actual discrepancy between what exists and what is wanted instead? Describe the discrepancies by listing a series of statements about the problem;

what are the facts as you see them? Mention persons, places and resources in your statements. Make sure your description of the problem allows for alternative solutions rather than just one of many possible options.

3. After identifying the problem, it is important to identify the causes or dimensions of it. What are the issues involved? What is the nature of the forces preventing movement from the actual state of affairs to the desired state? What forces might move us closer to the desired state?

4. The third step in problem solving is identifying alternative ways of solving the problem. Keep in mind that there are literally 360° of options or possible solutions. After brainstorming some of these, identify the pros, cons and risks involved with each.

5. After identifying and reviewing each solution and its positive and negative aspects, select the strategy you will implement (make a decision) and then determine the first step that needs to be taken.

6. Implementing a course of action and developing strategies for monitoring progress can be done with the help of the ACTION PLAN which follows this worksheet.

7. This worksheet may be helpful in situations where communication appears to be blocked due to differences in thinking and clarification of issues by the two or more people in conflict. Having each member of the family fill out a problem solving worksheet may help identify where the differences as well as the similarities lie. We may be quite surprised to discover that although our thinking pro-

were different, the acceptable solutions are actually quite similar. Then again, the acceptable solutions may be at opposite ends of the spectrum. Going through this or a similar clarification process, however, can be enormously helpful to a process of negotiation and eventual problem resolution. By involving all members of the family system in the problem solving process, we're more likely to get a well-rounded perception of the problem and possible solutions than if we were to try it on our own.

Our Problem Solving Worksheet

PROBLEM AS I SEE IT:

SPECIFIC ISSUES INVOLVED:

SOLUTION ALTERNATIVES	PROS	CONS	RISKS	ISSUES ADDRESSED
1.				
2.				
3.				

ALTERNATIVE SELECTED:

COURSE OF ACTION: (First step I will take to implement solution)

Our Family's Action Plan

Patricia A. Shank, Ph.D.

Once you have identified a solution or come to a decision about the general course of action you will take in solving a particular problem, it would be helpful to get the family together to write an ACTION PLAN.

SUGGESTIONS FOR USING OUR FAMILY'S ACTION PLAN:

1. Complete the PROBLEM SOLVING WORKSHEET.
2. Write the family goal in the space provided. For example, the family may have decided that the preferred solution to a problem concerning housework responsibilities is to distribute the chores among all family members. The problem isn't really solved until some action plan is constructed and followed and then evaluated along the way. In this case, the family goal could be: Implement a plan for completing household chores that includes all family members.
3. This goal should then be broken down into manageable tasks or steps that help the family meet the goal. Some steps that could taken in attempting to distribute household chores more evenly could be:
    1. Identify the tasks that must be done on a daily basis (e.g. dishes)
    2. Identify the tasks that must be done on a weekly basis (e.g. grocery shopping)
    3. Identify tasks that must be done every so often (e.g. wash the family car)

    Each step should be listed in the first column.
4. The next columns identify the specifics involved such as: when each step will begin, when it is expected to end, the name of the person responsible, who and what the person will need in order to complete the step, some obstacles that could prevent the person from completing

the task, and some solutions for overcoming those obstacles.

Using the same example above, we could write the following:

Step: Identify daily tasks

When Begin: 4/1/87 When end: 4/3/87

Person Responsible: Mom

Who/what Needed: other family members; paper, pencil

Possible obstacles: Might miss some tasks

Overcome Obstacles: Ask each family member to check list; add to it

5. On the bottom of the sheet is space for each family member to write his/her assessment of progress toward reaching the goal. In the action plan, identify when this evaluation will take place (list it as one of the steps). For example, the family may decide that they will evaluate whether or not the chores have been evenly distributed after one month has elapsed.

6. After the action plan has been completed, have each family member check it over. Some steps may need to be re-negotiated with the individuals or dates changed or other modifications made.

Our Family's Action Plan

FAMILY GOAL:

STEPS TO ACHIEVE GOAL OR IMPLEMENT SOLUTION/DECISION	WHEN BEGIN	WHEN END	PERSON RESPONSIBLE	WHO/WHAT NEEDED	POSSIBLE OBSTACLES	TO OVERCOME OBSTACLES
1.						
2.						
3.						
4.						
5.						
6.						
7.						
8.						

RATING OUR PROGRESS TOWARD REACHING OUR GOAL:

DATE: ______ ____________ name 100%/75%/50%/25% ____________ name 100%/75%/50%/25% ____________ name 100%/75%/50%/25% ____________ name 100%/75% 50%/25%

DATE: ______ ____________ name 100%/75%/50%/25% ____________ name 100%/75%/50%/25% ____________ name 100%/75%/50%/25% ____________ name 100%/75% 50%/25%

WE ACHIEVED OUR GOAL ON THIS DATE

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PEP

FILM AND THE FAMILY

by

Linda Brouillette

The family is the catalyst for the emotional well-being of its members and the very touchstone of our social structure. The plethora of interventions that have been designed to intercede into the lives of families bears testimony to these facts. Unfortunately many well meaning but externally imposed interventions have met with limited levels of success The family's own potential for preventing, as well as resolving, problems has scarcely been tapped (Coombs et al., 1984, p. 427).

One method any family can use to tap into this potential is through shared viewing and discussion of films. By increasing positive interaction and understanding among its members communication can be improved, thus preventing or resolving problems.

The influence of film on everyone, most particularly the young in our culture, has been widely documented (Amelio, 1971, p. 1-2). Family viewing and discussion of films can provide a positive channeling of that influence. Film can bring even the most divergent viewpoints within the family to a dialog. . By depicting how individuals in diverse situations view and cope with their worlds film enables families to reflect more deeply on their own experience.

The key to the most effective utilization of film for a family is in the discussion after it is viewed. Discussion helps to externalize the film experience into the structure of individual personalities and family life (Amelio, 1971, p. 9). A suggested guide family discussion might follow after viewing a selected film is outlined below.

1. Factual discussion of important, relevant, impressive scenes for each family member is helpful in the beginning. This enables family members to see varying viewpoints and concerns. It is important to remember, however, that simply the recitation of facts has little value.

2. Discussion should try to focus on individual family member's own position and attitudes toward the film and its characters.

3. Family members' feelings toward characters and the conflict of the film should be discussed. Differences and similarities among family members opinions should be explored together.

4. Discussion of how the film 's conflict and characters relate to the family should be explored. What aspects of family life and individual members does the film point up? What can the family learn from the film ? It is important to note here that relationships between aspects of the film and the family can always be found even if the film is not expressly about family life. Lessons and new insights for the family using this guide can be drawn from a wide variety of films.

The viewing and discussion of films together can become a positive and rewarding family activity. If it is to be successful the time required should be set aside on a regular basis. In addition, the family must have access to a VCR. Although growing numbers of families own VCRs they may also be rented from mamy local video stores.

Any film obtained from a local video store appropriate for family viewing can provide the basis for discussion. Generally owners of video stores keep lists with ratings of their films. Often they can give helpful suggestions for films to meet a family's needs and interests. Of course, Walt Disney films are always a good choice for family viewing and discussion. To get the family started the following pages contain information and discussion guides for three films easily obtainable in most video rental stores.

Happy viewing!

REFERENCES

Amelio, Ralph J. Film in the classroom. Why use it? How to Use It. Cincinnati, Ohio: Standard Publishing, 1971.

Coombs, Robert H. Enhancing Adolescent Development Via Family Intervention: A Filmography, Journal of Drug Issues. Spring, 1984.

Film: SAVANNAH SMILES

Source: Embassy Home Entertainment

Summary: This is a film about a young runaway girl and her development of a caring relationship with two bumbling small time crooks.

Comment: Heartwarming

To think about before viewing:

1. Have you ever thought of running away? What kinds of things make you feel this way?

2. What makes you happy? What makes your family as a whole happy?

Discussion questions after viewing:

1. Savannah's runaway note indicated she was unhappy. Why was she unhappy?

2. How did Savannah's time with Boots and Alvie differ from her time spent with her Mother and Father? How is free time spent in your family?

3. Boots and Alvie had nothing. During their time with Savannah they lived in a run-down abandoned house. Contrast this with Savannah's home. There was a great deal of difference yet Savannah was happy. Why? What in the two homes made the difference?

4. Boots and Alvie really listened to Savannah. How did they show her they listened? How did Savannah respond to this? How does your family listen to each other?

5. As Alvie and Boots really got to know Savannah they grew to care about her. How did they demonstrate that caring? How do you demonstrate caring for the members of your family? If you don't, what it makes it such a difficult task?

6. Knowing Savannah made it difficult to even take the reward money. Really knowing a person can change how you treat them. Do you really know the members of your family? Sometimes we can live together and not know each other.

7. A sense of loss underlies the emotions of many of the characters. How is each feeling loss? Have you ever felt loss like any of the characters? Were you able to come to terms with it?

8. Both Alvie and Savannah felt rejected by their families. Describe why each amy have felt this way. Have you ever felt rejected?

Film: Night Crossing

Source: Walt Disney Productions

Summary: This is a film about two families' struggle to escape from East Germany to freedom in the West by building a hot air balloon.

Comment: Intense suspense

To think about before viewing:

1. How important are goals for a family?

Questions for discussion after viewing:

1. In the note Lucas left for his family to read after his death he stated that he wanted them all to be together in a better place. Is your home a "better" place? What could make it a better place?

2. The two families worked together steadfastly in a partnership keeping their goal intact. How important is having a goal to work together to attain in a family?

3. What kind of setbacks did the families have along the way to fulfilling their plan? What setbacks have members of your family and the family together had? Despite the frustraion were you able to resolve the situation and move on ? How did you do this?

4. What were some of the doubts and fears Gunther's wife expressed regarding the escape plan? How did she overcome them? How do members of the family overcome their fears? Has fear ever altered any decision you have tried to make? How did it affect the decision?

5. Without taking the ultimate risk-the risk of their very lives the two families could never have been free. Why is risk taking important? Can we hope to reach our goals if we are afraid to take risks?

6. The Peters' children believed in their father even when he didn't believe in himself after the first unsuccessful balloon attempt. How important was the support the family provided him at that time? How important can a renewed belief in each other be for your family right now?

Film: Sylvester

Source: Columbia Pictures, A Rastar Production

Summary: This is a film about sixteen year old Charlie's struggle to bring up her two brothers while still managing to hang on to her dream of training show horses.

Comment: Some profanity, but an inspiring film.

To think about before viewing:

1. How important are goals? How much can we do to attain them? Is it ever better to give up or delay a goal?

Questions for discussion after viewing:

1. How did Charlie first come across to you in the begininING of the story? What qualities did she possess that helped her reach her goal?

2. Fear of change is a prevalent feeling for each person throughout the film. What changes does each fear? How does each handle it? Which person in the film do you most handle fear like? Why?

3. Why did Mr. Foster allow Charlie on different occasions to stumble and fall in her training 'with Sylvester? Why was it important for him to let these difficulties happen to Charlie?

4. Near the conclusion of the story Charlie was fearful of accepting Mrs. Hydes offer of learning to train horses for a year partly because she wouldn't fit in. Mr. Foster assures her that they will be fitting in with her after a year. How important is fitting in and being like everyone else to you? Can that need be a barrier to achievement?

5. Matt learned patience in waiting for Charlie to reach her goal as the film progressed? Her need to fulfill herself by reaching her goal while still making sure her brothers were provided for caused him to delay his goal of marrying her. How do you feel about that? What might that say about his growth as a person?

Boston University

School of Education
605 Commonweal[illegible]
Boston, Massachu[illegible]

Leisure Studies Prog[illegible]

Appendix A

May 21, 1985

Dear Parents, Guardians, and Professionals:

We are pleased to share with you our research on Educational Techniques pertinent to the lives of children with disabilities and their transition to community living. In an effort to [illegible] the need areas of our project, we are asking for your input.

We are collecting [illegible] following major target areas:

[illegible] n.

[illegible] to all [illegible] se [illegible] VIDED.

[illegible] e, [illegible] ted.

[illegible] ng to [illegible]

*Please check the type of agency or group that you are primarily affiliated with:

Hospital ___
Public School ___
Mental Health Center ___
Specialized School ___
Private School ___

Community Recreation Service Provider ___
Support Group ___
Respite facility ___
Community Treatment Facility ___
Other (please specify) ___________________

*Please check the category that describes your primary role:

Parent ___
Special Educator ___
Occupational Therapist ___
[illegible]
Case [illegible]
[illegible]

Psychologist ___
Social Worker ___
Administrator
[illegible]
[illegible] ___
[illegible]

[illegible]

Please note that throughout this survey the the terms listed below will denote the following:

children, child - child who is disabled

Related services - services other than instructional (such as transportation, developmental, corrective and other supportive services) that may be required to assist a child with disabilities to benefit from special education

IEP - Individual Education Plan

Networking - the creation of mutually beneficial relationships and exchanges among professionals, parents and counsumers; a sharing of time, ideas, resources, and equipment

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I. Please check the appropriate column that reflects [illegible] of the relative importance of the following aspects of [illegible] process.

			Not Applicable
1. [illegible] IEP development [illegible]	___	___	___
2. [illegible]		___	___
[illegible]			___
[illegible]			___
[illegible]			___
[illegible] visit [illegible] to			___

[illegible] statement [illegible]

[illegible] to it

				Not At All
[illegible] of social [illegible] child.			___ ___	___ ___
8. Instructional time devoted to social skills training into the school curriculum.	A.(impor) B.(avail)	___ ___	___ ___	___ ___
9. Participation of the entire family in recreation activities.	A.(impor) B.(avail)	___ ___	___ ___	___ ___

		Very	Some-what	Not At All
10. Training programs that teach how to use community resources independently.	A.(impor)	___	___	___
	B.(avail)	___	___	___
11. Materials that help parents develop their child's social skills.	A.(impor)	___	___	___
	B.(avail)	___	___	___
12. Materials that help teachers develop their student's social skills.	A.(impor)	___	___	___
	B.(avail)	___	___	___
13. Parent awareness of available local resources for the child and family.	A.(impor)	___	___	___
	B.(avail)	___	___	___
14. Parent use of the local resources for the child and family.	A.(impor)	___	___	___
	B.(avail)	___	___	___
15. Networking as a means of sharing [illegible] and knowledge about issues affecting children.	[illegible]	___	___	___
	[illegible]	___	___	___
16. A central resource for [illegible] tributing information [illegible]	[illegible]	[illegible]	___	___
	[illegible]	[illegible]	___	___
17. Provisions [illegible] families [illegible]	[illegible]	[illegible]	___	___
	[illegible]	[illegible]	___	___

III. In your opinion [illegible]

	[illegible]	[illegible]	Not At All
18. [illegible]	[illegible]	___	___
19. [illegible]	[illegible]	___	___
[illegible]	[illegible]	[illegible]	___
[illegible]	[illegible]	[illegible]	___

IV. [illegible] ments.

	[illegible]	[illegible]	Don't Know
[illegible]	[illegible]	[illegible]	___
[illegible]	[illegible]	[illegible]	___
24. Parents view recreation as an important service.	___	___	___
25. Teachers view recreation as an important service.	___	___	___
26. Therapeutic recreation is an effective way of meeting IEP objectives.	___	___	___

V. [illegible] "It is important to provide":

	Agree	Disagree	Don't Know
27. Pri[illegible] non-print materials for developing sup[illegible]r siblings of disabled individuals.	____	____	____
28. Materials for developing family cohesion through recreation and leisure.	____	____	____
29. Integration of the child into recreation and leisure programs in the community.	____	____	____
30. Incorporation of recreation [illegible] the individual education [illegible]	____	____	____
31. Development [illegible] and [illegible] trans[illegible]	[illegible]	[illegible]	____
32. [illegible]	[illegible]	[illegible]	____
[illegible]	[illegible]	[illegible]	[illegible]
[illegible] of [illegible] programs.	[illegible]	____	____
[illegible] An effective and comprehensive network of information sharing among parents.	____	____	____

		Very	Some- what	Not at All
43. [illegible] and comprehensive network of [illegible] sharing among parents and pr[illegible]als.	a.(imp)	___	___	___
	b.(avl)	___	___	___
44. An [illegible] information sharing [illegible].	a.(imp)	___	___	___
	b.(avl)	___	___	___
45. Education[illegible] to [illegible] by [illegible]	a.(imp)	___	___	___
	b.(avl)	___	___	___
46. [illegible]			___	___
			___	___
[illegible]			___	___
			___	___
[illegible]			___	___
			___	___

[illegible]at Not
[illegible]ant Important

___
___
___
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___

	Very Important	Important	Somewhat Important	Not Important
58. Devel[illegible] inservice training programs to i[illegible] awareness of disabilities for :				
a. [illegible]				
b. [illegible]ersons				
c. [illegible]l personnel				
d. physicians				
e. dentists				
f. attorneys				
g. hospital direct care staff				
h. other (specify) ____________				
59. Communicating with legislative representatives so that they will understand the needs of children who are disabled.				
[illegible]				

THANK YOU FOR YOUR EFFORTS IN COMPLETING AND RETURNING THIS STUDY

Appendix B

The Parent-Child Activity Group: Using Activities to Work With Children and Their Families in Residential Treatment

Gina DeSalvatore and Deborah [illegible]
New England [illegible] Hospital, [illegible], [illegible]

[illegible]

This article describes the development of a parent-child activity group on a psychiatric unit for latency-age children and discusses the group's usefulness as an assessment and treatment tool. Using an extended case vignette as an illustration, we integrate concepts from group and family systems theories to propose an innovative and replicable model for working with children and parents.

The Children's [illegible]

The children's [illegible]

with six families attending [illegible] six families attending on the second [illegible] are invited to participate in the group [illegible] The group is supplied [illegible]

until Mike's behavior escalated into school refusal, running away, stubborn and oppositional behavior, and aggressive outbursts toward her.

The topic that night was punishment and limit setting. After a general discussion on disciplining children, there was a role-playing activity in which the parent was to practice giving "timeout" [illegible] a boy who nagged and [illegible] his mother at the store [illegible]

[illegible]

[illegible] and poor peer [illegible] inability to [illegible] Steve threw a tantrum [illegible]

[illegible] and at times biting. Upon admission, Steve and his mother were [illegible] one of the parent-child groups.

[illegible] Prior to the start of the first session, the leader told them about [illegible] said that all would be working together as a "team" to help [illegible]. When asked what they would like to work on, Steve's [illegible] could not control Steve and would like to find other ways to [illegible] that he had a problem with his anger and that he would [illegible]

[illegible] noticed that when Steve's [illegible] to help him or [illegible] Steve would [illegible]" or just not [illegible] ask for help. [illegible] to his [illegible] his hand [illegible] apologiz-

[illegible] the [illegible] treatment [illegible] practice [illegible] expecta- [illegible] verbal [illegible] with him. In [illegible] identify his [illegible] aggression [illegible] increase his [illegible]

[illegible] format, in- [illegible] problem [illegible] intro- [illegible] to [illegible] One [illegible] as a [illegible] Finally, [illegible]

[illegible] play. Mother [illegible] Mother [illegible] her control

[illegible] and [illegible] play and [illegible] limits with [illegible] behavior. Because Steve appeared to be in